Interaction-Focussed Life Story Work in Semantic Dementia: A Mixed Methods Study

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ABSTRACT
The University of Manchester: PhD in the Faculty of Medical and Human Sciences
Jacqueline Ann Kindell: September 2015
Interaction-Focussed Life Story Work in Semantic Dementia:
A Mixed Methods Study

Background: Semantic dementia occurs as part of the frontotemporal dementia spectrum of conditions and presents with a progressive and striking receptive and expressive communication disorder. Studies thus far have generally concentrated on quantitative assessment of cognition and behaviour and there is a paucity of research examining conversation skills in everyday life, despite people with this condition and their family carers identifying this as the primary focus of their difficulties. There is also a gap in the literature in examining the first-hand experiences of people with semantic dementia and their family carers, in terms of how they live day to day with this condition. There is currently no evidence based advice for management of everyday communication issues in semantic dementia.

Aims: This thesis used a multiple case study design to explore everyday conversation at home with five individuals with semantic dementia and their spouses and in one case study, also a daughter. Individuals ranged from early semantic dementia to the advanced stages of this condition. Each case study used an innovative combination of conversation analysis of video and audio data alongside biographical interviewing in a longitudinal design. A total of 74 home visits gathered 45 hours of interview data and 12 hours of video data. Information derived from these strands was then used to design an individually tailored intervention which focussed on the specific everyday conversation issues in each situation. This included aspects of life story work and interaction-focused therapy.

Findings: A range of challenges and skills were present in the everyday conversations of these individuals with semantic dementia and their family carers. Some of this variability arose from differences in the severity of the semantic dementia across individuals in the study. However, differences were also apparent in how individuals with semantic dementia and their family carers adapted to the condition. Interaction-focused therapy was delivered in one case study, with measureable changes in post-therapy conversations at home. Life story work was delivered in all cases using a variety of formats. Analysis of outcomes highlighted that the work could be conceptualised under various points of connection: including interactional connections, emotional connections, building new connections, practical care connections and future connections. Cognitive, psychological and social factors impacted on the life story work. Creativity in practice was important to enhance not just information exchange but foster interaction using verbal, paralinguistic and embodied behaviours.

Conclusion: The study contributes to knowledge by providing in-depth understanding of the changes in everyday conversation for those living with semantic dementia and their family carers, as well as exploring interventions directly relevant for clinical practice. In this study both interaction-focused therapy and life story work offered promise to support and enhance adaptation to changes in interaction for all concerned. Aspects of both interventions, grounded in the study data, were proposed in an exploratory model to underpin ‘interaction-focused life story work’ in semantic dementia, i.e. life story practice with a central aim to enhance strategies for interaction in everyday life.
DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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DEDICATION

This thesis is dedicated to the people with semantic dementia and their family members who took part in this study and, also, to those with this condition I have worked with over the years. The sharing of their experiences has made this study possible and I thank them for this.

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I would like to thank my supervisors, Professor John Keady and Professor Ray Wilkinson for their expert support and guidance during this project and for everything I have learned from them along the way.

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I appreciate the support on this journey from all my colleagues in the Dementia and Ageing Research Team at the University of Manchester and particularly to Sarah Campbell and Lesley Jones for their encouragement and humour, particularly the latter.

I would also like to thank all my colleagues at Pennine Care NHS Foundation Trust, too many to mention, who have cheered me along and never doubted that practitioner research is an important path to challenge and improve practice in dementia care. Thank you to Laura Cole and Claire Leigh for covering my work during this time and to Carol Rushton and Brigid Flanagan for always being there when I needed you. I have shared and benchmarked my journey in dementia care with the Northern Speech and Language Therapy Special Interest Group in Old Age Psychiatry. I owe a great deal to the therapists in this group who continue to inspire me with their innovative practice.

Lastly, but most importantly, I would like to thank my husband Darren, my children Florence and William and my mum and dad for all their help over the years; without their practical and emotional support this study could not have happened.
BACKGROUND TO THESIS

The Personal Context
It is 1997 and I am a specialist speech and language therapist working in a community mental health team in inner city Manchester, visiting people with dementia. “You’re late,” Mavis (a pseudonym) said sharply as she opened her front door to our first meeting. I was surprised by this response for two reasons. Firstly, it was actually only 10.06 a.m. and the appointment we had made on the telephone the day before was for 10 o’clock. I felt, given I was only six minutes late, that it was a little odd to begin our first encounter with this observation. Secondly, I was actually very surprised that Mavis had remembered the details of my visit with this level of accuracy. This was because most of our team referrals were for people who were in the moderate to later stages of dementia and when visiting someone who lived alone, like Mavis, it was commonplace for the time and reason for a visit to be forgotten. Given this context, I was, therefore, taken aback by her ability to remember so well and I knew immediately that something was different here from my usual work.

Mavis invited me into her home and despite her initial sharpness, showed me great warmth. Working with Mavis and her family, and for a time becoming her key worker designated to coordinate her care, taught me a great deal about living with semantic dementia, the diagnosis Mavis was later given. This included the limitations of our understanding of this condition and the difficulty in tailoring services that were essentially configured around an understanding of dementia as a ‘memory problem’ with ‘confusion’. For example, the first care agency commissioned to work with Mavis was irritated that she expected them to arrive on time; regarding this expectation as unreasonable and questioned whether she had dementia at all if she could remember the time they were supposed to visit. A second care agency, however, appeared to cope better. As part of the care planning process meetings were held regularly with Mavis, the family, the general practitioner, the care agency and members of the community mental health team. We problem solved together, as there was no guidance for this specific practice and little evidence about how to direct support. Mavis, and those early encounters in 1997, was where my journey with semantic dementia began.
When I became ‘therapy manager’ in the Stockport Older People’s Mental Health Service in 2001, I supervised other staff (occupational therapy, physiotherapy, speech and language therapy and therapy support workers) working in the National Health Service with people with semantic dementia and, with other managers, I set up services for younger people with dementia. This gave me a broader service level view of semantic dementia. Over time, members of the community mental health team and therapy team in Stockport have developed considerable experience in supporting those with semantic dementia and their families. Yet contemporaneous understanding of semantic dementia remains dominated by the biomedical literature.

As I will explore later in this thesis, the move to hear the voice of the person with dementia seen in the general field of dementia care, with a few important exceptions, has often failed to access the experiences of those with frontotemporal dementia. Evidence based interventions are sparse or lack an exploration in a real world context. Therefore, aside from developments in the biomedical aspects of frontotemporal dementia, these conditions remain relatively understudied and at considerable risk of being left behind in the drive to improve services and interventions. In my experience, community mental health teams are still problem solving semantic dementia, as we did in 1997 and, therefore, clinically orientated research into semantic dementia is needed to guide and develop practice in this area.

**An Introduction to the Study and Study Aims**

The focus of this study is semantic dementia and interaction. It is an exploratory intervention study where I worked as both a clinician and researcher which resulted in areas of reflexivity and on-going clinical supervision throughout the duration of the empirical encounters (from August 2012 to September 2014). The thesis presents an early attempt to develop and evaluate a range of biographically-driven interventions that aim to support and enhance the quality of interaction at home for people living with semantic dementia and their family carers.

As I will explain in Chapter 3, the original overarching design to achieve these objectives was through a case series design (Smith, 2012) using a consistent method of intervention and measurement of outcome. This method was adapted from interaction-focussed therapy within the field of aphasia (Lock et al., 2001; Wilkinson...
and Wielaert, 2012) with advice situated within a biographical context derived from a life story approach (McKeown et al., 2006; Moos and Björn, 2006). However, it became clear in the clinical encounters with the first two recruited families that this systematic method of intervention required refinement and a more flexible design was needed. Therefore, as will be explained, a case study design (Yin, 2009) was chosen as this facilitated more flexible clinical decision-making and allowed creativity and innovation to be part of each longitudinal clinical encounter. I retained consistent approaches within each case study to allow for cross-case comparison, such as life story data gathered through interviews, analysis of interaction from video and audio data, observation in the home setting and neuropsychological assessments.

As a consequence, the study delivered five unique and innovative case study interventions in semantic dementia that had measurable components, however exploratory, with data analysed using the methods of conversation analysis (Hutchy and Woofitt, 2008) and narrative analysis (Phoenix et al., 2010; Riessman, 2008; Sidnell, 2010). Reaching this plateau was not as straightforward as this text makes it appear and some of the challenges I encountered included:

- The lack of systematic research in the field to guide practice in either interaction-focussed therapy or life story work.
- Identifying the tasks that it would be feasible to deliver within the study timescales and time-limited nature of the study funding, given the mixed methods and intervention design.
- Gaining ethical approval for a study using video to collect data and involving those who may lack capacity to give consent for themselves.
- Managing the diversity of the chosen methods and the resulting extensive and in-depth data set.
- Making sense of, and triangulating, the data from various sources.
- Utilising the scope and range of the literature on which the study is predicated.
- Presenting a coherent story of the practitioner-conducted research.

In discussion with my PhD supervisors, I have, therefore, had to make a number of informed choices in the presentation of this thesis. The literature from which the
study draws is diverse and extensive and I have, therefore, chosen to present a
general discursive review of the literature in Chapter 1 to set the contextual frame for
the study and then explore through a substantive literature review those studies that
particularly explore conversation and interaction in dementia in Chapter 2. I have
used applied conversation analysis that has clinical utility (Antaki, 2011; Guendouzi
and Müller, 2006); however, as I also have other data and intervention analyses to
present, I am unable to present numerous examples of every conversation practice as
would be common in conversation analytical studies (Fox, 2014; Jones, 2012).
Therefore, to maintain theoretical and epistemological rigour, I will present
additional conversation examples in the Appendix and/or present a summary of the
analysis in the text. Due to the richness of the data set, particularly the video data, I
have identified other areas of analysis that could be undertaken and these are
highlighted in the text.

Organisation of Thesis
This thesis has six chapters:

Chapter 1 provides a discursive literature review providing the frame for the study.
This includes the current policy context for dementia as well as a description of
semantic dementia, consideration of life with the condition and interventions so far
suggested in the literature or that may offer potential. By providing this context for
semantic dementia, I will illustrate the current research and practice in this area,
including strengths and the associated gaps. As the study of semantic dementia is a
developing field, consideration is given to this condition, the spectrum of other
conditions within frontotemporal dementia, the general dementia care literature and
relevant work in the field of aphasia therapy.

Chapter 2 presents the substantive literature review undertaken for this study
examining the area of everyday interaction in dementia. This is approached through
a systematic search and synthesis of the literature using a method developed
specifically for conversation based studies (Parry and Land, 2013). By presenting the
evidence this way, I will outline what is known about conversation in semantic
dementia and frontotemporal dementia as well as what is known, and can be learned
from, the general dementia care literature. I illustrate how, despite a great deal being written about communication in dementia, the study of interaction in natural situations, particularly with family carers, remains an emerging field.

**Chapter 3** presents the methodologies and methods used within this study. I discuss the rationale for conversation analysis and narrative analysis, including the reasons for choosing, and mixing, these methods within this study. Issues of reflexivity and rigour will also be addressed. I will describe the strategy for study recruitment and eligibility, along with practical aspects of data collection and analysis. This study presented considerable methodological and ethical challenges and these are addressed in this chapter.

**Chapters 4** presents the five case studies. In each case study the person with semantic dementia participated alongside their spouse and in one case, case study two, the couple’s daughter also agreed to take part in the intervention stage of the research. Data collection in each case study was carried out longitudinally over an extended period of time, ranging from seven months to 18 months. Case studies are presented in the order in which participants were recruited into the study. In each instance I will describe the specific interactional issues and needs within each situation and how these were addressed within the intervention, with an exploration of the outcomes in each case.

**Chapter 5** presents the cross cutting issues evident across the five case studies including issues with respect to interaction and how individuals and couples adapted to changes in communication. Further analysis of interventions is provided. A model for the delivery of life story work in semantic dementia aiming to improve interaction, interaction-focussed life story work, is described arising from these cross cutting themes.

**Chapter 6** describes the findings from this study, explores how these relate to the current literature in semantic dementia and demonstrates their contribution to knowledge for this condition. This includes examining the everyday challenges with conversation uncovered in this study and how the person with semantic dementia and their family carer adapted to changing needs in this area. The interventions delivered
in the study are examined. Issues of performance are discussed and how this potentially relates to the representation of semantic dementia, along with the methodological advances in this study with respect to analysis of music to enhance interaction. The limitations of the study are outlined. The chapter concludes with a summary of the recommendations for practice, research, policy and education in semantic dementia.

**Definition of Terms and Writing Conventions Used**

The following terms and conventions have been

- The thesis has been written in the first person to allow for consideration of my role, practice and reflection within the study.
- This thesis uses the term semantic dementia, rather than semantic variant primary progressive aphasia or temporal variant frontotemporal dementia. Frontotemporal dementia is used as a generic term to encompass the spectrum of conditions: semantic dementia, nonfluent primary progressive aphasia and behavioural variant frontotemporal dementia. Where only the behavioural presentation of frontotemporal dementia is referred to, I have used behavioural variant frontotemporal dementia.
- With a few exceptions, numbers from one to nine are written within the text in full, with numbers 10 and above written in numerical form.
- I have used the Harvard style of referencing. Where there are two authors these are cited and where the are three or more ‘et al.’ has been used. Authors are presented in alphabetical order in the text and the bibliography. Within the bibliography each publication outlines a full author list.
- Direct quotes from participants have been indented and italicised in the text if the quote extends beyond 40 words. Shorter quotes are embedded in the text using double quotation marks and are also italicised.
- When writing the names of the couples engaged in this study I write the person with semantic dementia in the first position and the spouse in second, e.g. Peter (person with semantic dementia) and Joanna (spouse), whenever names appear together.
- Abbreviations used (except at the start of a sentence or in titles) include USA = United States of America
UK = United Kingdom
NHS = National Health Service
I = Interview
F = Field note
V = Video data
T = Telephone

- Brackets are used to refer to the type of data source and the date this was gathered, e.g. (I 11/07/13) = interview given on the 11th July 2013.
- Conversation excerpts are transcribed using conventions from conversation analysis (Jefferson, 2005) and a Key to Symbols is contained in Appendix 1.
CHAPTER 1

Semantic Dementia in Context

1.1 Introduction
This opening chapter will outline the current context for the PhD study, including broader policy and practice considerations. A discursive review of the literature is provided aiming to contextualise this study within the broader knowledge base including that of frontotemporal dementia, dementia care and aphasia therapy. The chapter begins with the current policy context for dementia. The symptoms of semantic dementia are described, in particular the changes in language evident in this condition. The experience of living with semantic dementia for the person concerned and their family carers is explored, along with knowledge about this area within the general field of dementia care. Lastly, interventions for semantic dementia are discussed, including those aimed at this condition and potential interventions from dementia and aphasia that could be adapted to this area. This review highlights that interventions studied in semantic dementia to improve communication have often focussed on word finding skills through experimental studies of word relearning, largely derived from performance on neuropsychological tests. Whilst interventions delivered in the general field of dementia care, such as life story work and communication training for family carers may offer potential, the specific delivery of such interventions has not been systematically explored in semantic dementia.

1.2 Definitions and Demographic Data
Dementia is a syndrome associated with a progressive decline in a range of brain functions leading to problems with memory, language, understanding and judgment (NHS Choices, 2015). Dementia is therefore an umbrella term caused by a range of conditions including more common dementias, such as Alzheimer’s disease and vascular dementia and rarer dementias, such as frontotemporal dementia (Alzheimer’s Society, 2015). Frontotemporal dementia, or frontotemporal lobar degeneration, encompasses three conditions: one that presents with changes in behaviour and personality: behavioural variant frontotemporal dementia and two that
present with changes in language skills: semantic dementia and nonfluent primary progressive aphasia (Gorno-Tempini et al., 2011; Neary et al., 1998; Rascovksy et al., 2011). As the latter two conditions present with progressive changes to language they may be grouped together under the heading of primary progressive aphasia (Gorno-Tempini et al., 2011). The term ‘semantic dementia’ was first used by Snowden et al. (1989) although features of the condition had been described previously (Pick, 1904; Sasanuma and Monoi, 1975; Warrington, 1975). Semantic dementia may be classified, particularly within the North American and Australian literature, as fluent progressive aphasia (Adlam et al., 2006; Blair et al., 2007) or, more recently, as the semantic variant of primary progressive aphasia (Gorno-Tempini et al., 2011).

Alzheimer’s Disease International (2012) estimate that 36 million people in the world are living with dementia with a projected increase in 2030 to 66 million. Whilst frontotemporal dementia is believed to account for between 2-3% of all such cases of dementia, it is thought to be a significant cause of dementia in those under 65 years of age (Alzheimer’s Disease International, 2012). The rates of semantic dementia within frontotemporal dementia are unknown, with variable reports, e.g. 20% (Hodges et al., 2010), 10% (Kertesz et al., 2010), 25-33% (Hodges and Patterson, 2007). Hodges et al. (2010) found a mean age at diagnosis of semantic dementia as 64.2 years (range 40-79 years), with 46% of individuals presenting after 65 years, arguing that whilst semantic dementia generally presents at a younger age compared to Alzheimer’s disease, the condition may be particularly under recognised in older people, or misdiagnosed as Alzheimer’s disease.

1.3 Dementia: Service and Policy Context
There has been a considerable interest in dementia in recent years, with both the national and international policy context developing rapidly. In England, the five-year National Dementia Strategy (Department of Health, 2009) set out specific recommendations from the government for the NHS, local authorities and others to improve dementia care. Within the strategy there were three overarching themes: raising awareness and understanding; early diagnosis and support; and living well with dementia. In 2012, the UK Prime Minister, David Cameron, outlined a
challenge to dementia care and research, that included provision of improvements in health and social care, creating dementia friendly communities and improving dementia research by 2015 (Department of Health, 2012), recently updated with a target date of 2020 (Department of Health, 2015). An important strand to this work has been the development of ‘Dementia Friends’ (2015), a charity set up by the Alzheimer’s Society and Public Health England aiming to develop public awareness and understanding of dementia. Implicit within recent policy approaches is the need to move beyond understanding dementia as solely a disease of the brain to a more holistic understanding that encompasses psychosocial aspects, including the lived experience of those with dementia at all stages of the condition (Brooker, 2007; Kitwood, 1997a; Sabat, 2008).

The various policy initiatives have seen an improvement in awareness and understanding of dementia (Alzheimer’s Society & Public Health England, 2015; Department of Health, 2009; Department of Health, 2015). However, I would argue that this awareness is a generic representation of dementia, built largely upon understanding the needs of those with common dementias, such as Alzheimer’s disease and vascular dementia, with a lack of detail about different presentations of dementia and associated needs. Less common dementias, such as frontotemporal dementia, are often not mentioned in practice and policy guidance beyond differential diagnosis; for example, within the National Institute for Health and Clinical Excellence and Social Care Institute for Excellence clinical guideline for dementia (2006) frontotemporal dementia is specifically mentioned only within differential diagnosis and genetic issues, all sections on interventions are assumed to cut across all dementia subtypes.

1.4 What is Semantic Dementia?

Semantic dementia presents with a progressive and striking receptive and expressive communication disorder, arising from progressive erosion of semantic memory affecting all modalities (Kashibayashi et al., 2010; Mayberry et al., 2010; Snowden et al., 1989). Neuroimaging studies reveal bilateral, often asymmetrical, damage to the anterior temporal lobes, an area of the brain regarded as crucial for the processing of semantic knowledge (Hodges et al., 2010; Hodges et al., 1992; Neary
et al., 1998; Patterson et al., 2007). Expressive speech in semantic dementia is described as fluent with word finding difficulties, semantic paraphasias and an increasing lack of content words as the disease progresses and is, therefore, often referred to as ‘empty’ of content (Harciarek and Kertesz, 2011; Hodges and Patterson, 2007; Kertesz et al., 2010). In contrast to Alzheimer’s disease, visuospatial skills are relatively well preserved in semantic dementia (Harciarek and Kertesz, 2011; Hodges et al., 1992; Kertesz et al., 2010) and, although episodic memory does become impaired with time, difficulties are often described in retrieving remote, rather than recent, day to day memories (Hodges and Patterson, 2007; Hou et al., 2005; Nestor et al., 2002).

It is thought that changes in semantic memory are responsible for these difficulties in language (Hodges and Patterson, 2007). Semantic memory is the brain’s store of conceptual world knowledge including information about the objects and words we use, accumulated over time (Hodges and Patterson, 2007; Tulving, 1972). This is in contrast to episodic memory, the store of personal memories specific to a particular time and place (Hodges and Patterson, 2007; Tulving, 1972). In semantic dementia the changes with semantic memory are regarded as a central conceptual deficit. This is an important point because it is not just difficulties accessing knowledge that is thought to lead to symptoms, but loss of the knowledge itself. For this reason, difficulties present with understanding and using words; however, the symptoms extend beyond words and this affects recognition and understanding of all other stimuli, including objects, faces, sounds, smells, touch and tastes (Bozeat et al., 2000; Bozeat et al., 2003; Bozeat et al., 2002; Hodges and Patterson, 2007; Luzzi et al., 2007).

Changes in personality and behaviour are commonly described in semantic dementia (Harciarek and Kertesz, 2011; Hodges and Patterson, 2007; Neary et al., 1998; Rankin et al., 2008). Different patterns of right and left temporal lobe damage have been associated with different behavioural profiles (Mion et al., 2010; Seeley et al., 2005; Thompson et al., 2003). As the condition progresses there is often bilateral temporal and frontal involvement and so overlap occurs with the behavioural variant of frontotemporal dementia, in terms of changes in behaviour and personality (Bozeat et al., 1999; Kertesz et al., 2010; Liu et al., 2004; Rohrer et al., 2008).
However, some behaviours have been reported to be particularly prominent in semantic dementia including compulsive behaviours such as adherence to routine, ‘clockwatching’ and complex routine behaviours (Snowden et al., 2001).

Reported changes in behaviour that may be relevant to communication include: socio-emotional behavioural difficulties (Rosen et al., 2006); irritability (Rohrer and Warren, 2010); a lack of social warmth (Rosen et al., 2002); a lack of empathy (Rankin et al., 2005b); disinhibition (Mendez et al., 2006; Rohrer and Warren, 2010); difficulty understanding emotions (Rosen et al., 2002); difficulty with affective and cognitive theory of mind tasks (Duval et al., 2012a); heightened gaze with reduced physiological arousal to emotion (Sturm et al., 2011); and prominent complex stereotyped behaviour (Nystanza et al., 2003). There is little evidence of any positive attributes reported in the existing literature.

1.5 Communication in Semantic Dementia

Studies examining communication in semantic dementia have largely focussed on the language disorder seen on cognitive testing, most commonly exploring the conceptual difficulties evident at a single word level, with a smaller range of studies examining connected speech and aspects of discourse, as I will now outline.

1.5.1 Single Word Level Issues in Semantic Dementia

A significant number of studies have explored single word processing, in order to explore the changes in lexical semantics evident in the condition, within both expression and comprehension (Hoffman and Lambon Ralph, 2011; Lambon Ralph et al., 2001; Mayberry et al., 2010); it is these difficulties that largely underpin differential diagnosis (Gorno-Tempini et al., 2011). Difficulties in naming various stimuli are evident on testing, with semantically related errors, for example, Hodges and Patterson (2007) report when asked to name a picture of a zebra, in the earlier stages an individual with semantic dementia may say ‘a giraffe’ and as the condition progresses ‘a horse’, then ‘an animal’ and finally with further progression ‘I don’t know’. Such semantically related difficulties are also evident in understanding and so the same individual may point to a giraffe when given an array of animal pictures and asked ‘which one is the zebra?’ It has been argued that in the earlier stages of the
condition such difficulties affect low frequency words and concepts, but as the condition progresses difficulties occur with common everyday concepts that underpin activities of daily living (Gorno-Tempini et al., 2011; Hodges et al., 2010; Warren, 2013). The research group led by Snowden and Neary, however, has a long standing view that personal experience has a role in maintaining concepts and vocabulary in semantic dementia (Snowden, 2015a; Snowden et al., 1994; Snowden et al., 1995) and that this explains why some individuals retain certain low frequency vocabulary items that are of personal relevance. Julien et al. (2010) have argued that ‘in semantic dementia more abstract levels of meaning degrade, revealing semantic representations that are tightly bound to an individual’s current autobiographical experience’ (p.279).

1.5.2 Connected Speech, Discourse and Conversation
Connected speech samples have been generated with a view to analyse semantics and syntax using picture description, telling familiar stories and structured interviews (Bird et al., 2000; Garrard and Forsyth, 2010; Hodges, 2001; Kave et al., 2007; Meteyard and Patterson, 2009; Wilson et al., 2010). The semantic difficulties with word retrieval seen on single word tasks have also been described in these connected speech samples; with difficulty in retrieval of lower frequency words, increased use of vague and empty terms, pronouns and deictic terms, e.g. ‘this one’, ‘that one’ (Bird et al., 2000; Garrard and Forsyth, 2010; Kave et al., 2007). However, Sajjadi et al. (2012) explored connected speech in picture description and semi-structured interviews and found that whilst there was a decrease in pictorial themes within picture description, two thirds of the individuals with semantic dementia they studied did not show evidence of talking around words (circumlocution) on either task; a supposed hallmark of the condition on naming tests and assumed to be present in connected speech (Kertesz et al., 2010). The authors interpret these findings by noting that individuals with semantic dementia may ‘avoid speaking about concepts for which knowledge is severely degraded, analogous to healthy people who do not make conversation about concepts that are unfamiliar to them’ (Sajjadi et al., 2012, p.15). The authors conclude that when individuals with semantic dementia have more autonomy over topic choice, their talk is less likely to sound aphasic.
A preservation of syntax, in the face of this semantic loss, is often described in semantic dementia in both expression of sentences (Bird et al., 2000; Breedin and Saffran, 1999; Kertesz et al., 2010) and understanding of syntax (Rochon et al., 2004). However, recent reports have questioned this assertion (Benedet et al., 2006; Meteyard and Patterson, 2009; Wilson et al., 2010) and there has been a shift to describe a ‘relative’ sparing of syntax with an absence of ‘gross’ syntactic errors (Meteyard and Patterson, 2009).

Research examining discourse and conversation skills in semantic dementia is less apparent. Different patterns of change in discourse have been reported across the frontotemporal dementias. In semantic dementia problems with word retrieval, impaired linguistic fluency and semantic comprehension problems have been reported; while in behavioural variant frontotemporal dementia difficulties with organisation, pragmatic disturbance and tangential output are more common (Ash et al., 2006; Chapman et al., 2005; Cosentino et al., 2006). In contrast, Orange et al. (1998) used topic directed conversation interviews with individuals with frontotemporal dementia and primary progressive aphasia to analyse the resulting discourse quantitatively. Surprisingly, perhaps, severe pragmatic problems were seen in the non-fluent progressive aphasic group, with more subtle issues in the fluent group (likely to represent those with semantic dementia), whilst pragmatic performance of subjects with behavioural variant frontotemporal dementia was well preserved (Orange et al., 1998); findings at variance with reports of behaviour and speech (Neary et al., 1998).

Reports of changes in conversation skills in semantic dementia are apparent in the literature, for example, speech has been described as ‘garrulous, excessive, disinhibited output,’ with individuals ‘perseverating on their own agenda and not stopping to listen’ (Kertesz et al., 2010, p.487). However, such reports are largely anecdotal with a lack of explanation as to how such judgements are made. There appears to be only one study systematically examining everyday conversation in semantic dementia (Kindell et al., 2013), which I will return to in the next chapter.

Together, these studies demonstrate some of the inherent problems with aggregating data from different individuals, at different stages, with potentially different, but also
overlapping, conditions. There are also a number of problems in assuming that the
pattern of skills or difficulties seen in experimental tasks and structured interviews
will be the same in conversation at home. Such tasks differ from natural conversation
because the topic is pre-determined by the ‘examiner’ and behaviour is constrained
by the situation with a focus on information exchange rather than other reasons for
talking and with a lack of consideration of the behaviour, or relationship, of the co-
speaker (Perkins et al., 1998). Additionally, verbal responses are required with no
opportunity to use compensatory strategies including nonverbal communication.
There is evidence that individuals with semantic dementia may perform differently if
the topic of conversation is an area of personal relevance (Julien et al., 2010;
Snowden, 2015a; Snowden et al., 1995). I will return to the literature examining
interaction and frontotemporal dementia in more depth in the next chapter.

1.6 Living with Semantic Dementia: The Person and Their
Family
A number of authors have highlighted that a purely biomedical approach to dementia
care has significant limitations (Brooker, 2007; Kitwood, 1997a; Kitwood, 1998;
Nolan et al., 2004; Sabat, 2008). The experience of the person with dementia is
central within person centred care approaches (Brooker, 2007; Kitwood, 1997a) and
the relationships important to the person with dementia paramount in relationship
centred approaches (Nolan et al., 2004). Whilst recognising that the underlying
changes within the brain are a factor influencing behaviour in dementia, Sabat
(2008) has argued that psychological and social factors equally play a part. He,
therefore, advocates a ‘bio-psycho-social’ model that also includes the person with
dementia’s reaction to their condition and the ways in which they are treated by
healthy others, in addition to biological changes (Sabat, 2008). Progressive dementia
care practice would, therefore, take into account the lived experiences of both the
person with dementia and their family members when planning support and
interventions.

1.6.1 The Experience of the Person with Semantic Dementia
In the general dementia literature studies have explored living with dementia
following a diagnosis and issues of self and identity (Caddell and Clare, 2010;
Steeman and Dierckx de Casterle, 2006). However, few studies have involved people with frontotemporal dementia in their sample (although see: Keady and Nolan, 2003; Menne et al., 2002; Pratt and Wilkinson, 2001). To date, the literature examining living with frontotemporal dementia remains sparse with only one recent study exploring the specific experience of those living with behavioural variant frontotemporal dementia (Griffin et al., 2015). Griffin et al. (2015) reported in their study of five people living with this condition that individuals showed some awareness of changes in their behaviour and lifestyle. However, participants experienced difficulties in making sense of these changes and relating them to their medical diagnosis. This subjective experience was described as distinct from that seen in Alzheimer’s disease because, whilst the descriptions of changes in their situation was in some ways similar, there was a lack of the associated ‘reflective and emotional understanding’ usually evident in Alzheimer’s disease (Griffin et al., p.17). Other studies have also focussed on examining life within a particular diagnosis, rather than dementia in general, illustrating that this line of enquiry is promising to deliver understanding of the lived experience within specific dementia diagnoses (Keady et al., 2009; Williams and Keady, 2012).

Caddell and Clare (2010) note that most studies exploring issues of ‘self’ in dementia focus on those with Alzheimer’s disease or unspecified diagnoses of dementia. In their review, studies involving people with frontotemporal dementia were only found within quantitative studies examining ‘self as self-knowledge’ and they advise there is a need to explore qualitative issues in conditions other than Alzheimer’s disease, such as frontotemporal dementia, and longitudinally (Caddell and Clare, 2010). Two studies were consistent in their findings that individuals with behavioural variant frontotemporal dementia described their personality as it had been in the past, before their dementia, whilst their relatives indicated this self-knowledge was out of date (Rankin et al., 2005a; Ruby et al., 2007). Lack of insight or awareness has, however, been described as less extensive in individuals with primary progressive aphasia syndromes compared to behavioural variant frontotemporal dementia (Banks and Weintraub, 2008; Eslinger et al., 2005). With respect to semantic dementia, Duval et al. (2012b) found that present identity seemed to be preserved but that the ability to think about oneself in the future was impaired,
i.e. the person they might become, likely to be because future thinking involves semantic as well as episodic representations.

Qualitative research in dementia generally has demonstrated that there is persistence of at least some elements of ‘self’ into the late stages of dementia and interactional aspects are key to examining this area (Caddell and Clare, 2010). Information has been derived from natural conversations (Angus and Bowen, 2011; Cicourel, 2011; Sabat and Collins, 1999; Shakespeare, 2004; Small et al., 1998; Tappen et al., 1999), observation of verbal and nonverbal communication in natural situations (Fontana and Smith, 1989; Hubbard et al., 2002; Kontos, 2004), unstructured interviews (Surr, 2006b) and co-constructed narratives in conversation (Ramanathan-Abbott, 1994). Mills (2006; 1998) noted that although people with advanced dementia may not be able to tell their own story, understanding of this by others allowed for continuation of the biographical self through them. Surr (2006b) argued that ‘the quality of interpersonal relationships is an essential component of preservation of self and therefore should be considered a crucial element in dementia care that aims to uphold self’ (p.1721).

Examining other sources of literature, it appears that autobiographies written by people with frontotemporal dementia, of any kind, are rare (Page and Keady, 2010), and although personal blogs and accounts by individuals with frontotemporal dementia have begun to be seen on the internet (Fay, 2003; Glick, 2015) the current focus of information and support remains largely carer orientated.

In summary, the general dementia literature shows that a variety of methods can be used to explore the lived experience of those with dementia and issues of self and identity. Whilst one recent study has explored living with behavioural variant frontotemporal dementia (Griffin et al., 2015), this work has yet to be carried out in semantic dementia. Given the overlap between behavioural variant frontotemporal dementia and semantic dementia, particularly in the later stages of the condition, there may be similarities in subjective experience. However, the quantitative literature indicates that insight may be less affected in the earlier stages of semantic dementia and so exploration of such issues specifically in this condition is required to design sensitive and appropriate interventions.
1.6.2 The Experience of Family Carers in Frontotemporal Dementia

The literature examining family carers’ experiences is largely quantitative, examining issues of carer stress and burden, and often correlating this with behavioural features evident in the person with frontotemporal dementia. Two studies have, however, explored experience from a qualitative perspective in semantic dementia and behavioural variant frontotemporal dementia (Kindell et al., 2014b; Oyebode et al., 2013) and I will discuss these after presenting relevant aspects of the quantitative literature.

A review carried out by Nunnemann et al. (2012) found an increased burden in carers of people with frontotemporal dementia compared to those with Alzheimer’s disease, and that this burden was correlated with particular neuropsychiatric symptoms. Carers of people with frontotemporal dementia, compared to Alzheimer’s disease carers, have been shown to have reduced marital satisfaction (Ascher et al., 2010), higher levels of depression (Kaiser and Panegyres, 2007; Mioshi et al., 2009) and burden (Boutoleau-Bretonniere et al., 2008; de Vugt et al., 2006), less satisfaction with the person with dementia and themselves as carers (de Vugt et al., 2006) and greater levels of need (Nicolaou et al., 2010). One of the issues within the literature is that often different variants of frontotemporal dementia are not separated out and this may give an inaccurate picture across the clinical spectrum. A recent study that did attempt this, found that carers of people with behavioural variant frontotemporal dementia were markedly more burdened than those caring for people with semantic dementia and nonfluent progressive aphasia (Mioshi et al., 2013a).

Atypical dementias also present a challenge in terms of obtaining a timely diagnosis and appropriate service provision, and this can impact on the carer (Chemali et al., 2010; LoGiudice and Hassett, 2005; Morhardt, 2011; Rosness et al., 2008). Semantic dementia presents at an earlier age than that seen in more common dementias such as Alzheimer’s disease, and so the impact on the family may be different. Studies examining carers and families of younger people with dementia have discussed issues arising from a different phase in life including: issues with employment, family conflict, financial difficulties, effects on children and difficulty
accessing a diagnosis (Allen et al., 2009; Cabote et al., 2015; Roach et al., 2008; Svanberg et al., 2011; van Vliet et al., 2010).

Turning to the qualitative literature, in a case study of a family caring for an individual with semantic dementia, Kindell et al. (2014) used narrative analysis and identified four themes within the caregiving experience: (a) living with routines, (b) policing and protecting, (c) making connections, and (d) being adaptive and flexible. Learning to live with the practical and conversational routines that ‘Doug’ had developed along with his semantic dementia was an important aspect to his wife and son’s experience. The family described their constant mental and physical vigilance in monitoring behaviour and talk within the theme of ‘policing and protecting’. Their attempts to keep Doug connected to the social world were encompassed within ‘making connections’. Overall the theme of ‘being adaptive and flexible’ illustrated their journey with semantic dementia and how they had adapted to the changes in Doug. In this respect, there was discontinuity with the past and at times descriptions of change rather than of loss. Within the general dementia carer literature, maintaining continuity with the past has often been emphasised as important for relationships and a shared identity (Montenko, 1989; O'Shaughnessy et al., 2010; Perry and O’Connor, 2002) and this issue of continuity and discontinuity in their experience was one of the distinct challenges in adapting to semantic dementia for this family.

Oyebode et al. (2013) interviewed six relatives of people with behavioural variant frontotemporal dementia and, using interpretive phenomenological analysis, demonstrated 11 themes. Five themes related to witnessing bizarre and strange changes including: changes in appetite and drives; lack of forward planning; loss of inhibition leading to socially embarrassing behaviours; risky behaviour because of a lack of common sense and judgement; and communication problems. Four themes related to managing these behaviours including: taking on tasks and roles; defending, asserting and explaining; promoting quality of life; and working around a lack of awareness. A final two themes were: loss of the person and relationship, and heartbreak; sources of support, solace and hope.
There is some overlap in themes between the work of Oyebode et al. (2013) and Kindell et al. (2014), particularly with respect to changes in communication and loss of inhibition, leading to socially embarrassing behaviours. In both studies, despite such behaviours, carers used strategies aiming to promote the quality of life of the person with frontotemporal dementia. Both studies also note issues of continuity and discontinuity with the past, arising out of changes in personality and behaviour.

The focus of the quantitative literature in frontotemporal dementia on issues of stress and burden in some ways mirrors the dementia literature during the 1980’s and 1990’s when such issues were studied extensively (Zarit and Zarit, 2008). Since then, however, it has been established that carer experience is multidimensional and includes a variety of factors beyond the behaviour of the person with dementia including context, culture, relationship dynamics, support structures, personal coping resources and the meanings individuals assign to their experiences (Brodaty and Donkin, 2009; Hayes et al., 2009; Hibberd et al., 2009; La Fontaine and Oyebode, 2014; Lin et al., 2012; Roach et al., 2014b). In addition, the literature has also highlighted that, along with the challenges present in caring, some individuals also report satisfaction in their ability to perform their role as a carer and personal growth arising from this (Robertson et al., 2007). Identifying the various relevant factors relating to the person with dementia, the carer and the context in which they live is an important part of intervention for carers (Brodaty and Donkin, 2009; Elvish et al., 2012; Pinquart and Sorensen, 2006), and there seems no reason to doubt this is also the case in frontotemporal dementia.

1.7 Interventions in Semantic Dementia

Following an examination of the available literature, I have chosen to present this area under three headings arising from the main focus of the intervention(s):

1. Broad approaches to care and support involving a multidisciplinary focus and family carer support.

2. Specific interventions targeting word finding, generally in progressive aphasia syndromes, including semantic dementia.

3. Other interventions and potential avenues to innovative practice.
1.7.1 Broad Approaches to Care and Support

Community mental health team practice would aspire to deliver a comprehensive approach to support the person with dementia and their family carers. This multidisciplinary focus is described by Wylie et al. (2013) in their description of mental health practice in frontotemporal dementia, considering issues from diagnosis, around driving, carer support, community support, residential care and end of life care. Kortte and Rogalski (2013) also argue for a team based approach focussing on adapting to changes in function along with consideration of activities and participation in daily life. Although there is a lack of research underpinning their advice, Kortte and Rogalski (2013) advocate for a range of approaches including: calendars and organisers for a person in the earlier stages of frontotemporal dementia; assessment and advice from occupational therapists around self-care tasks; advice around communication from speech and language therapy; structure to the routine; consideration of the environment and issues of safety and risk; and activity groups to provide stimulation. Shnall et al. (2013) describe a day care service for people with frontotemporal dementia with a range of activities and use an observation checklist to examine behaviour and facial expression during such activities. Kindell et al. (2015) examined the practice of speech and language therapists working with people with semantic dementia and noted that these therapists had a broad approach that was delivered in partnership with the person with semantic dementia, their family and friends together with practitioners in health and social care.

Reviews of frontotemporal dementia that discuss intervention(s) often focus on the lack of proven drug therapies followed by stressing the need for carer support, with little attention paid to support for the person living with frontotemporal dementia (Jicha, 2011; Léger and Johnson, 2007; Warren, 2013). Studies examining such carer support and training programmes are relatively few in number and often focussed on relief of stress and burden through understanding and managing behaviour, recognising particular stressors and developing coping strategies (Banks et al., 2006; Diehl et al., 2003; Mioshi et al., 2013b; Weintraub and Morhardt, 2005). Some studies have examined the delivery of support and education programmes via video-conferencing facilities (Damianakis et al., 2008; Dowling et al., 2014; O'Connell et
Lastly, support groups aimed at the primary progressive aphasia population may include both the carer and the person with the condition, including those with early semantic dementia (Wieneke et al., 2012). This is the case with the only support group of this kind in the UK (Primary Progressive Aphasia Support Group, 2015).

### 1.7.2 Specific Interventions Targeting Word Finding

In terms of specific interventions to target the communication difficulties evident in semantic dementia, the most common focus in the literature is improvement of word retrieval through practice of target words. This arises from the view that problems in word retrieval are the most significant factor in communication difficulties in semantic dementia. Whilst reviews of these methods have shown that there is improvement in treated words, compared to non-treated words within the experimental design, debate remains about issues of maintenance and generalizability (Carthery-Goulart et al., 2013; Croot et al., 2009; Jokel et al., 2014). For example, regular practice is required to maintain these gains and learning is often context specific with a lack of proven generalisation to other settings, including conversation (Jokel et al., 2014). One study has documented generalisation of trained words to a video description task (Savage et al., 2014). However, the differences between video description and ordinary conversation have been highlighted in another study, where generalisation gains in other forms of primary progressive aphasia could not be demonstrated (Croot et al., 2015).

### 1.7.3 Other Interventions and Potential Avenues to Innovative Practice

Bier et al. (2009) advocate a move away from a focus on word finding to one restoring specific and functionally relevant underlying concepts, with one study demonstrating the reacquisition of a favoured recipe in an individual with semantic dementia (Bier et al., 2011). Cartwright and Elliot (2009) worked in a group situation using a format of structured television viewing and discussion within sessions and were able to show that individuals with semantic dementia were able to recall a greater number of story information units in their discourse post-therapy. In a case study, Wong et al. (2009) used a discourse based intervention with carer
training to help foster communication using residual abilities, including non-verbal communication in a man with semantic dementia, with some promising, albeit descriptive, outcomes.

There are some interesting studies highlighting that skills with music, painting or other artistic pursuits may be preserved or altered in frontotemporal dementia (Hailstone et al., 2009; Miller et al., 2000; Miller et al., 1998; Warren et al., 2011; Weinstein et al., 2011). For example, a heightened liking for music has been particularly noted in semantic dementia, with this behaviour described as ‘musicophilia’ in the literature (Fletcher et al., 2013). These case reports have been examined for implications for diagnosis or broader studies of the neurobiology of music within the human brain (Boeve and Geda, 2001; Hailstone et al., 2009; Miller et al., 2000). Weinstein et al. (2011) describe a professional musician who, despite semantic dementia and severe communication difficulties, could skilfully play a range of pieces on the harpsichord. Hailstone et al. (2009) noted a woman with a significant degree of semantic dementia had begun to spend increasing amounts of her time listening to pop songs. Both studies suggested there was preservation in music ability, in contrast to knowledge of words and objects, and that this had important implications for models of knowledge within the brain. There are also some interesting case studies of music therapy with individuals with frontotemporal dementia. Ridder and Aldridge (2005) in a case report describe how Mrs F, with advanced frontotemporal dementia, enjoyed singing familiar songs and a reduction in heart rate and antipsychotic medication was noted over the four week programme. In a later report, Ridder et al. (2009) explore various measures to develop a research protocol for music therapy in frontotemporal dementia.

Preservation of visual skills has been argued to contribute to reports of artistic talent (painting, sculpture, photography) in frontotemporal dementia (Miller et al., 1998). Rankin et al. (2007) studied visual art production in dementia and noted group differences with compositions produced by individuals with semantic dementia to be judged as more ‘bizarre and distorted’ perhaps because individuals are ‘freed from representational constraints and social expectations of what art should look like’ (p.60). A more recent study, however, has questioned whether the artistic talent seen
in frontotemporal dementia is truly creative suggesting instead that this can be explained by the release of involuntary behaviours (Cruz de Souzaa et al., 2010).

Less well understood is what the increased interest in music, or art, means for the individual with frontotemporal dementia and their family or the implications this has for activity and intervention. In some case reports, the behaviour is presented as a behaviour that challenges; for example, in Boeva and Geda (2001), the individual concerned is described as sitting in his car and listening to Polka music for between 12-18 hours a day. However, there is no sense as to whether the man derives any pleasure from this activity, or indeed, if he did not do this, what other opportunities would be available to him.

1.8 Therapeutic Approaches from Dementia Care

There is little guidance in the literature or in clinical guidelines as to if, or how, therapies used across the field of dementia care can be applied to semantic dementia. Whilst dementia care has moved to consider the lived experience of the person with dementia and to deliver interventions that take account of this, as I have discussed, the literature in frontotemporal dementia remains largely focussed on the experience of the family carer. The delivery of philosophies of person centred care (Brooker, 2007) and relationship centred care (Nolan et al., 2004) and interventions stemming from such approaches have not been systematically explored with respect to semantic dementia. Common interventions used in dementia care include reminiscence, life story work and communication skills training (Eggenberger et al., 2013; McKeown et al., 2006; Westerhof et al., 2010). However, it is not clear if, or how, such interventions can be used in semantic dementia. For example, whilst advocating a person centred approach, the Eastern Cognitive Disorders Clinic in their Frontotemporal Dementia Toolkit (2014) have suggested that reminiscence may not always be appropriate for people with frontotemporal dementia due to differences in the presentation of recent and long term memory difficulties. I will now describe life story work and communication skills training, two approaches commonly used in dementia care currently and particularly relevant for this study.
1.8.1 Life Story Work

Life story work has been described as ‘an approach to working with a person and/or their family to find out about their life, recording that information in some way and then using the information with the person in their care’ (McKeown et al., 2015, p.239). Currently, life story work is popular in clinical practice with a variety of templates aiming to gather life story information (Kindell et al., 2014a). The approach is increasingly noted in policy, for example, life story work was identified as beneficial in care settings for communication and relationships within the National Dementia Strategy for England (Department of Health, 2009). A range of life story formats are often discussed in research and guidance (McKeown et al., 2013), however, in clinical practice, life story books are most commonly used (Kindell et al., 2014a; McKeown et al., 2006).

In their systematic review on life story work in health and social care, McKeown et al. (2006) state that while there appear to be many positive benefits to life story work, the literature is ‘immature’ with a ‘lack of critical debate about the use of life story work in practice’ (p.241). A further complication is that definitions of life story work vary, with overlap in approaches including: life review, biographical approaches, oral history, life history and reminiscence work. Two reviews of life story work published in the same year, as a result, produced a strikingly different set of papers (McKeown et al., 2006; Moos and Björn, 2006).

Whilst life story work may aim to improve the care of a person with dementia, relatively few studies explicitly set out to evaluate outcomes from the perspective of the person with dementia, perhaps arising from a focus, particularly in earlier studies, on work within institutional settings. For example, studies may use focus groups or interview methods to explore the experience of staff and family carers (Clarke et al., 2003; Hansebo and Kihlgren, 2000; Kellett et al., 2010). Subramaniam and Subramaniamay et al. (2014) in contrast, examined the experience of people with mild to moderate dementia in care homes in a randomised control trial of life story work, and found that residents benefitted whether they had been involved in a life review process to make their life story book or had been given their book as a gift. Once the life story books were in place, there were positive effects on quality of life,
personal memory and staff attitudes. Less clear was whether the books had any effects on relationship issues or how the books influenced communication. Another study demonstrated that there were challenges in involving people with more advanced dementia who may lack the required skills with memory and language to reflect, and report on, the development and use of their life story books (McKeown, 2011).

Whilst studies carrying out life story work in community settings are smaller in number there are signs that the approach may be promising. Ingersoll-Dayton et al. (2013) explored the ‘couple’s life story approach’ with 24 couples, 22 of whom were living in their own homes and found that the intervention was feasible to deliver across five sessions in most cases and, using questionnaires, they identified positive aspects and challenges for practice. Keady et al. (2005) engaged in life story work in a memory clinic setting to explore and improve clinical practice and service delivery.

Some of the challenges reported in life story work include issues of: disclosure of very personal stories, ‘who’s story is it?’ when a person with dementia is not involved in the life story process, the variable quality of life story resources, whether books are over- or under-used (McKeown et al., 2015) and whether the process may lead to upsetting memories, or reminders of activities now lost due to dementia (Ingersoll-Dayton et al., 2013). At present the literature fails to give any consideration about whether particular cognitive issues might impact on life story work. For instance, given the focus on Alzheimer’s disease, it is perhaps surprising that no mention is made of the way spatial or perceptual difficulties might impact on the use of photographic and pictorial material. More recently, there has been interest in how technology may be used within reminiscence and life story work to increase interaction (Purves et al., 2015).

Improvements in communication are a recurring theme in the literature and this has generally been explored using observation and discourse analysis. McKeown (2011) for example, used observation or discussion with the person with dementia whilst they were looking through their life story book. However, one of the challenges inherent in observation remains the difficulty for researchers in recording the finer details of interaction, through written notes, with studies often reporting on more
global aspects such as mood and levels of engagement rather than examining how
the life story product contributed to interaction in detail.

In the USA, Bourgeois and others have pioneered the use of ‘memory wallets’ or
‘memory aids’ most often within residential settings, using discourse analysis to
explore the effects (Bourgeois et al., 2001; McPerson et al., 2001). Similar to life
story books, memory wallets contained personally-relevant pictures and sentence
stimuli surrounding facts about the person with dementia, listed in a chronological
manner from long term memories through to recent statements. A number of
quantitative studies showed an improvement in aspects of conversation when using
the memory wallet/aid with spouses (Bourgeois, 1990), staff (Bourgeois et al., 2001)
and in conversations with other people with dementia (Bourgeois, 1993), compared
to conversations without the aid. Such results are encouraging and a recent
systematic review of methods to enhance verbal communication between carers and
people with Alzheimer’s disease noted that, of all the interventions surveyed, the use
of memory wallets combined with specific carer training programmes, emerged as
potentially the most effective approach (Egan et al., 2010).

Closer analysis of the data, however, indicates a degree of variability, with some
participants doing less well with their aid, often those with more advanced dementia
(McPerson et al., 2001) and different conversational dyads showing distinct
discourse styles with and without their aid (Bourgeois, 1993). In one study husbands
did not report any positive effects on conversation on the measures used and some
were observed to exhibit overly corrective behaviours when engaged in training with
the memory aid (Bourgeois, 1990).

Conversation analysis has been used to study interaction before and after training (a
one hour workshop) between a man with dementia and his daughter, talking using a
memory book made by the researcher. Following training the father took a more
active part in the encounter but the authors caution that advice and training are
required as the format may encourage behaviours such as labelling and listing of
materials (Spilkin and Bethlehem, 2003).
Aside from the study by Spilkin and Bethlehem (2003) the studies analysing memory wallets use aspects of discourse analysis to examine, and to change, verbal behaviours; for example, counting number of turns, number of utterances, on topic statements, factual statements, ambiguous, error and unintelligible utterances etc. There is, therefore, a heavy focus on measures of information exchange and factual content, using transcribed data taken from audio recordings. Less well explored are the broader issues of interaction including important embodied behaviours. Baker (2002) in her practice report on the use of life story work within continuing care NHS wards, warns practitioners not to undervalue the non-verbal responses that life story books may elicit, going on to say ‘I was particularly moved by the actions of an almost non-verbal gentleman who fondly stroked his wedding photograph. His wife said that was the first sign of any recognition he had shown in weeks. This simple act kept her spirits going during the times ahead, when his condition deteriorated further’ (p.4).

The literature examining memory wallets also does not address enjoyment during such activities. This is reflected in the review carried out by Moos and Björn (2006) who divide life story studies into three categories: i) interventions to change self-esteem and self-integration, ii) interventions to change quality of life, and iii) interventions to change behaviour, with the studies measuring memory wallets/aids listed under the last category. Moos and Björn (2006) conclude their review, noting that whilst studies showing changes in behaviour have made an important contribution to the field, a move to more rigorous quantitative designs runs the risk of focussing on a narrow set of impacts and, given that there is still much to learn about how to ‘deliver sensitive, individualised and effective support and care to people with dementia, it is argued that qualitative assessments have been too hastily discontinued’ (p.431).

There appear to be no studies specifically exploring life story work in semantic dementia or frontotemporal dementia. The use of picture boards and other items to support participation in conversation has been discussed for those with primary progressive aphasia, often within the field of augmentative and alternative communication, i.e. low and high technology communication aids (Fried-Oken et al., 2010; Rogers and Alarcon, 1998; Rogers et al., 2000). It is unclear whether such
approaches are suitable for all types of primary progressive aphasia, with the current focus of experimental studies largely, it appears, aimed at nonfluent progressive aphasia (Fried-Oken et al., 2010). It has, for example, not been established whether the underlying conceptual loss that characterises semantic dementia presents particular challenges in the symbolic systems used with picture boards evident in the work of Fried-Oken et al. (2010).

There are indications that life story work is being used in clinical practice in frontotemporal dementia. For example, Kindell et al. (2015) noted that speech and language therapists were adapting and using life story work within their practice with individuals with semantic dementia. In their frontotemporal dementia toolkit the Eastern Cognitive Disorders Clinic (2014) note the importance of life story as part of holistic person centred assessment, using the model in Figure 1.1 to understand symptoms and behaviour. This has been developed from the ‘CAUSED’ model arising from unpublished work by Alzheimer’s Australia.

Figure 1.1 – The CAUSED model in frontotemporal dementia

There is often a focus within life story work and biographical approaches on engaging the person with dementia in talking about their past life in order to influence current care (see for example: Clarke et al., 2003; McKeown et al., 2006; Moos and Björn, 2006). One of the appeals within this approach arises from the relative preservation of long term memories, in comparison to recent memories,
evident in Alzheimer’s disease and, therefore, that individuals are often more successful in talking about topics from their long term past (Ripich et al., 1999). This highlights two aspects that may be particularly relevant when considering adapting the approach to semantic dementia. Firstly, there may be challenges for individuals in talking about such experiences due to the prominent communication difficulty evident in semantic dementia. Secondly, given that a different pattern of memory has been described in semantic dementia, with evidence for recent memory being less affected by the condition (Hodges & Patterson, 2007), it is not clear in what way a focus on the long term past might influence current conversations and care practices. Kindell et al. (2014), for example, suggest that life story work in semantic dementia may need to be adapted to reflect a focus on more recent memories.

It would seem, therefore, that life story work may have potential for those living with semantic dementia but that further research is required. With a lack of critical debate on life story work generally in the dementia literature to guide this work, it would seem that the advice of Moos and Björn (2006) might be particularly pertinent when adapting approaches to those with semantic dementia and that a qualitative approach would allow for a broader view to explore the complexities of the issues at hand. The use of conversation analysis by Spilkin and Bethlehem (2003) also demonstrates that specific attention to the interactional aspects of life story work is required.

1.8.2 Communication Skills Training

Providing communication skills training to staff and family carers around the communication needs of people with dementia is very common in dementia care settings, either as part of broader training programmes about dementia or stand-alone courses focussing on communication. However, in a systematic review of this area, Eggenberger et al. (2013) note that whilst some studies appear promising, inconsistencies remain with methodological flaws and a lack of validated communication outcome measures available to measure the effects of training. Young et al. (2011) note that ‘the vast majority of advice and most of the communication tools or training programmes currently available make no explicit link to any theoretical framework’ (p.1007), with an absence of any underpinning communication theory or empirical basis with a top-down, writer/trainer perspective.
As a result, Young et al. (2011) consulted people with dementia and their family carers in the development of their communication toolkit and discussed particular models of communication theory where the aim was to enhance communication by appropriate accommodation within interaction to the communication changes in a given individual (Giles et al., 1991; Ryan et al., 1995).

However, whilst it is important to consult widely in the development of such resources, there is a question as to whether reflecting on communication is enough and whether direct observation may be needed. For example, Small et al. (2003) studied audio recorded conversations at home of people with Alzheimer’s disease engaged in activities of daily living with their spouses and found that the strategies carers reported as using were not always present in their communication. Some strategies reported as helpful in the literature, such as slowing speech rate, did not appear to be helpful at observation. Lastly, the authors warned that strategies that might reduce communication breakdown might have other negative psychosocial consequences, thus ‘reducing distractions’ might potentially reduce pleasurable activities and ‘using yes-no questions’ could lead to reduced choice. Young et al. (2011) also note that within such generic programmes or advice schedules, there is often little advice in how to tailor the generic advice to the needs of particular individuals.

Currently, advice about communication needs in semantic dementia remains anecdotal (e.g. Frontotemporal Dementia Toolkit, 2014; Snowden et al., 2006) and it is not clear whether the atypical underlying language difficulties evident in the condition, makes general advice for communication in dementia less applicable to semantic dementia. Snowden et al. (2006) note, for example, that the common advice to keep utterances simple may not benefit individuals with semantic dementia because they do not, in the mild to moderate stages, have difficulty with syntactic processing and simpler utterances may reduce semantic content and, inadvertently, impact negatively on understanding. Taking advantage of preserved domains of function is also reported in this advice and again, in contrast to advice for those with Alzheimer’s disease, recent memory and references to time may support understanding (Snowden et al., 2006). Such advice is professionally driven and derived from observation in clinical practice. There are, however, few studies
exploring the everyday difficulties and skills present in semantic dementia (Kindell et al., 2013) on which to base more ecologically grounded advice and no studies at all directly examining the communication strategies used by carers. There is, therefore, much to learn about potential strategies to support communication in semantic dementia.

In the field of aphasia resulting from stroke, therapies to support conversation have been explored in more depth and, in particular therapies that provide individually tailored, rather than generic, advice. Simmons-Mackie et al. (2014) review such approaches within aphasia therapy and note different philosophical, theoretical and practical roots including: social and participation models, functional and behavioural orientations, counselling-orientated approaches and conversation analysis. For example, an increasing literature has emerged using conversation analysis to assess and enhance the conversation of particular dyads in natural settings, especially at home. Such approaches are described as ‘interaction-focused’ therapy (Wilkinson, 2010; Wilkinson et al., 2010b; Wilkinson and Wielaert, 2012). Practical resources arising from such approaches include Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC) (Lock et al., 2001) and more recently, an online resource, Better Conversation with Aphasia (Beeke et al., 2013b).

This approach has been advocated for dementia care (Perkins et al., 1998) with a clinical resource based on conversation analysis produced: Conversation Analysis Profile for People with Cognitive Impairments (Perkins et al., 1997). However, this resource and the approach in general, have not been systematically explored in dementia care. Simmons-Mackie et al. (2014) state that an important aspect to interaction-focused approaches is the goal of co-constructed meaning and management of social relationships rather than traditional notions of linguistic accuracy and it is this, in particular, that might be appealing for dementia care. In addition, interaction-focused approaches are underpinned by theory derived from conversation analysis and are inherently individualised, therefore addressing many of the problematic issues within the dementia care communication literature highlighted by Young et al. (2011). I will return to this theme in my next chapter, a review of the literature with respect to dementia and interaction.
1.9 Summary and Conclusion

This chapter has provided a description of semantic dementia and the current context of the condition within the broader field of dementia care, as well as interventions currently examined in the literature. This introduction, however, illustrates that interventions are often driven by researchers or clinicians with no exploration of the preferences of people with semantic dementia and their family carers with respect to intervention, or to broader service issues with this client group. There is also very little research exploring the everyday experiences of people with semantic dementia and their families in order to design and deliver sensitive interventions. It seems logical that bio-psycho-social models of dementia (Sabat, 2008), or those advocating person centred care (Brooker, 2007) or relationship centred care (Nolan et al., 2004), could be applied to semantic dementia; however, this has not been systematically explored and interventions arising from such approaches, including life story work and communication training, will need to be adapted.

Experimental quantitative studies examining aspects of the language disorder evident in semantic dementia have been discussed in this chapter. This includes linguistic features such as word finding difficulty and ‘empty speech’ seen in word retrieval tasks (Hodges and Patterson, 2007). Hamilton (2005) discusses different approaches to the study of language in dementia and refers to such experimental approaches to the study of language as ‘the prism,’ i.e. the aim is to separate out linguistic phenomena that are then ‘analysed apart from other linguistic or social phenomena, with no specification of a relationship to the speaker or the context of talk beyond possible straightforward correlations’ (p.231). To date, this approach has dominated the study of communication in semantic dementia. This has led to interventions from this standpoint focussing on word relearning tasks. Some researchers have attempted to study the different aspects identified in the ‘prism’ in a more integrated manner in a whole discourse approach. An example of this would be the study of connected speech in semantic dementia by Sajjadi et al. (2012). Referring to this as ‘the soliloquy’, Hamilton (2005, p.232) notes that this ‘disembodied discourse’ focusses only on the person with dementia and takes no account of conversation as a co-constructed process, dependent on others. Lastly, Hamilton identifies two other broader approaches. ‘The couch’ signifies work that explores personal meaning
making and the construction of identity through conversation. ‘The dance’ refers to those approaches that focus on conversation as a co-constructed process between two or more speakers, rather than as a product of the person alone and, as in a dance, the moment-to-moment interdependence between speakers is of paramount interest. These latter two approaches present with important implications for intervention because implicit is the notion that the behaviour of others can potentially support conversation and identity. However, the study of language from this perspective has made relatively little impact within therapeutic approaches in semantic dementia or indeed frontotemporal dementia in general; it is this perspective that underpins this thesis.

In the next chapter the focus of this thesis turns to an in-depth exploration of conversation viewed as an everyday, contextualised and co-constructed behaviour in the substantive literature review. This review will examine issues of conversation and interaction in dementia currently within the literature in order to inform this study, including assessment of need and the interventions aiming to enhance conversation: interaction-focussed therapy and life story work.
CHAPTER 2

Conversation in Dementia: A Review of the Literature

2.1 Introduction
This chapter will provide a substantive review of the current literature concerning conversation in dementia. As discussed, this thesis is focussing on everyday conversation and interaction in semantic dementia and potential interventions to support this; however, research specifically examining conversation in semantic dementia is sparse. Therefore, as in the previous chapter, literature has been drawn from studies in frontotemporal dementia and the general dementia literature in order to understand the current state of knowledge in this area from closely related fields and to inform the assessments and interventions within this study. The scope and strategy of the review using a method specifically designed for conversation studies will be outlined (Parry and Land, 2013). Studies will be presented exploring conversation in Alzheimer's disease, vascular dementia and Lewy body dementia, followed by those studies exploring conversation in frontotemporal dementia. Lastly, useful methods and concepts from this review will be described, as well as the gaps and challenges for this study and dementia care in general.

2.2 Methods - Search and Review Strategy
In this chapter I have followed the method developed by Parry and Land (2013) for systematically reviewing conversation analytic and related literature. This method is aimed at teams of systematic reviewers and I have, therefore, adapted the method, which is presented in Table 2.1. I have chosen this method because of the tool's focus on conversation research, rather than use a more generic qualitative appraisal tool, such the Critical Appraisal Skills Programme Checklist (CASP, 2014). This is because Parry and Land (2013) argue that the nature of evidence from conversation analytical and related research is different from other qualitative work. Moreover, results are generally descriptive and specific in nature, rather than aiming to interpret and generate theory. Parry and Land (2013) suggest that knowledge from conversation analysis has not been adequately translated into healthcare policy,
education and practice and a significant aspect of this has been the low number of reviews in this area, particularly those using systematic methods.

Table 2.1 - Steps in the literature review adapted from Parry and Land (2013)

1. **Articulate purpose of review & audiences, review question(s) and scope**

2. **Specify eligibility criteria**
   - Studies must rely on fine grained analysis of audio/audio-visually recorded naturalistic interaction.
   - Devise other criteria, including settings, language etc.

3. **Search for studies**
   - Use electronic databases.
   - Design, test and refine word groups for database searches.
   - Scan included publications against eligibility criteria.
   - For difficult cases read in detail.

4. **Describe the characteristics of included studies**
   - Uni-dimensional quality appraisal is not possible for this kind of evidence instead record: characteristics of data, settings, participants, analytic approach and depth.
   - Design customised templates for collecting this information.

5. **Data extraction – using the templates designed**

6. **Collate and synthesise data**
   - Read data extraction forms.
   - Organise and combine findings into logical categories.
   - Consult with wider literature in relation to practices identified.
   - Derive implications for the review audience and identify gaps in the evidence.

7. **Sensitivity and subgroup analyses**
   - Retrospectively assess the contribution of different sets of publications.

8. **Reporting the review**

Parry and Land (2013) set out to design a method that could be specifically used to systematically review conversation data, an ambition in line with the aims and value-base of this thesis. This method does not aim to generate new theory, but to aggregate findings to draw out clinical, policy and educational implications (Parry and Land, 2013). Therefore, the focus of this review and chapter will follow each of
the eight steps in Table 2.1. The first seven steps will describe the process of the review and this will be followed by the final step of this process, where the results of this review will be presented (step eight).

### 2.3 STEP ONE: Articulate Purpose of Review & Audiences, Review Question(s) and Scope

As I have outlined in the background and introduction, this study is aiming to develop a greater understanding of everyday interaction in semantic dementia and interventions aiming to support interaction, provided by dementia practitioners and researchers. The purpose of this literature review is to inform both the research and practice based elements of this study. The audience is, therefore, essentially community dementia practitioners and clinical researchers who work to support individuals with semantic dementia by providing, or researching, psychosocial interventions. Such practitioners work within a bio-psycho-social framework, i.e. one that recognises the cognitive difficulties present in dementia, but also considers the broader psychosocial environment in the process of delivering therapy and support (Spat, 2008). As I have discussed, I have chosen to focus the scope of the review on the broader literature examining conversation and interaction in dementia care, rather than just the narrower field of semantic dementia or frontotemporal dementia. This is because of the small number of studies in the field and because this approach encompasses important contributions in the field that may inform this study. Parry and Land (2013) suggest formulating a review question to guide and drive the purpose of a review and therefore after considering the purpose, audience and scope of the review, the following question has been used: In what way(s) can the literature examining everyday conversation in dementia inform the work of practitioners and clinical researchers, working within a bio-psycho-social framework, with people with dementia and their families?

### 2.4 STEP TWO: Specify Eligibility Criteria

Eligibility criteria were as follows:

- Studies must examine everyday conversation occurring in an environment familiar to the person with dementia, e.g. own home, residential home, day centre using:
Conversation analysis with qualitative or mixed qualitative and quantitative analysis.

- Adapted conversation analysis, or other methods, e.g. structural functional linguistics where the analysis is predominantly qualitative or mixed qualitative and quantitative and conforms to the following:
  - Data driven rather than hypothesis driven.
  - Analysis arises from the data rather than predetermined systems of coding.
  - Involves analysis across turns between at least two speakers.
  - Involves presentation of conversation samples in findings/results.
  - The focus of study is on conversation itself and the part both parties play to develop the conversation or the narrative within it.

- Conversations can be with family, volunteers, paid carers or researchers.
- Methods must allow for the conversation to develop in a naturalistic manner rather than follow a structured question and answer format and allow for the person with dementia to take an active part in developing topics and ideas within the conversation.
- Studies must be reported in English examining mono-lingual conversations.
- Papers must be published within peer reviewed journals and book chapters.

### 2.5 STEP THREE: Searching for Studies

Exploratory searches were undertaken to develop an appropriate search strategy, considering appropriate databases, search terms and search fields. As well as searching the literature about everyday conversation in dementia, it became clear during this step that supporting people with dementia to tell stories about their lives, within conversation, also represented an overlapping body of literature important to this study and therefore conversational storytelling in dementia was also explored.

#### 2.5.1 Conversation Area 1: Everyday Conversation in Dementia

The following search terms were used: ‘conversation* OR discourse AND dementia OR primary progressive aphasia’. Searches were carried out for these terms in the abstract (‘all field’ searching leading to unmanageable figures and ‘key words’ yielding very low numbers). The following data bases were searched: OVID multiple
database search (Medline, Amed, PsycINFO, Social policy and practice, Books@Ovid, PsycBooks) which led to 582 titles after duplicates were removed. In order to ensure no literature had been omitted from the nursing and social science literature additional searches were undertaken in the following databases (brackets indicating titles found): ASSIA (11 titles), Web of Science (600 titles), CINHAL (119 titles). References within papers were explored and the journal ‘Dementia: The International Journal of Social Research and Practice’ was searched using ‘conversation’ as a key term. Following inspection of each title and abstract, 87 publications were retrieved for further inspection and checked against eligibility criteria and 38 titles remained after this process.

2.5.2 Conversation Area 2: Conversational Storytelling in Dementia

Due to the variety of terms (stories; storytelling; conversation; conversational) in this area the following terms were used in ‘all field’ searching:

- Conversation* AND story* AND dementia
- Conversation* AND narrative AND dementia.

The following databases were searched: OVID multiple database search (Medline, Amed, PsycINFO, Social policy and practice, Books@Ovid, PsycBooks), which led to the following number of titles: 1124 and 562 (respectively) after duplicates were removed. Further searches were carried out to examine the nursing and social science literature using the same search terms in the following resources (brackets indicating titles found): CINHAL (26, 18), Web of Science (26, 17), ASSIA (5, 0). After checking titles and abstracts 18 publications were retrieved in full and after checking against eligibility criteria a core of nine titles remained.

The review therefore consisted of a total of 47 titles.

2.6 STEP FOUR: Describe the Characteristics of Included Studies

Parry and Land (2013) describe the challenges in quality appraisal of conversation analytical research arguing that current tools are inadequate for this task because ‘conversation analytic perspectives, methods and findings are incompatible with the binary categories – qualitative and quantitative - familiar in healthcare research’
For example, there is no generation of numerical data to appraise as in quantitative approaches and neither is there generation of theory, or interpretation of meaning, as is often the focus in qualitative approaches using interview data. Therefore, when designing templates to facilitate the review process I followed recommendations from Parry and Land (2013) to include: aspect of conversation studied, setting, participants, approach used including number of examples, depth, outcome and reviewers notes. In this way I focussed on Parry and Land’s (2013) advice to consider two dimensions in relation to each study’s value and contribution: 1) the type and amount of data and 2) the detail and depth of analysis. I also added ethical issues, an area not addressed in Parry and Land (2013), but present in the qualitative CASP tool (CASP, 2014). I chose to add this because of the complexity of this issue in dementia care, particularly for those people with dementia who lack capacity (Mental Capacity Act, 2005).

2.7 STEP FIVE: Data Extraction – Using the Templates Designed
I read each paper and completed data extraction forms designed in step four. Forms were completed for all 47 titles. Examples of these forms are provided in Appendix 2, in order to illustrate this step.

2.8 STEP SIX: Collate and Synthesise Data
This step was driven by the review purpose and question and involved drawing together and summarising studies. I read the data extraction forms, referring back where necessary to the original papers to identify the strengths and limitations of each paper and general issues with respect to quality within the literature. I considered and recorded how the findings related to the broader dementia literature, or not, and the literature with respect to semantic dementia and frontotemporal dementia to expand the insights generated from the review. I used my understanding of community dementia practice to draw out concepts that might be useful to inform practice based research in this area and recorded these. I then organised the material into logical categories and subgroups in a way that might best inform the review question and identified strengths and gaps in the literature, including recurring issues with respect to critical appraisal. There were potentially numerous ways to organise the literature review, with a variety of overlapping areas. The diversity of the
conversation practices described meant that grouping studies by particular conversation practices was not appropriate. Given the focus of this research, I therefore chose to keep studies into Alzheimer’s disease, vascular dementia and Lewy body dementia separate from studies examining frontotemporal dementia.

2.9 STEP SEVEN: Sensitivity and Subgroup Analysis

I organised the studies according to the categories identified at step six and further explored the contribution of different sets of publications in order to further explore subgroup analysis. Within the general dementia literature, I chose to keep studies separate depending on a number of factors including early seminal studies in the field, studies that particularly drew on certain theories or methods such as positioning theory and conversation analysis, and other studies with a more general focus on language use in context or other sociolinguistic theory. As I have discussed, storytelling in conversation was an overlapping area and I have kept this separate. Formulaic language appeared to have some overlaps to the recurring routines reported in conversation in semantic dementia (Kertesz et al., 2010; Kindell et al., 2013; Kindell et al., 2014b) and so this area was also explored separately. Lastly, studies were identified where conversation was the target for individualised, rather than generic advice, in keeping with the overall aims of this study.

Studies within the frontotemporal dementia literature were divided into those exploring progressive aphasia and semantic dementia and, alternatively, the behavioural variant of frontotemporal dementia. A final section mapping across all studies identified useful concepts from the literature and, secondly, identified those areas that required further attention arising from the critical appraisal process. In this way both the strengths and the limitations across the literature review were drawn together and reported as a whole rather than for each paper.

2.10 STEP EIGHT: Reporting the Review

The remainder of this chapter now encompasses the last step of this process, step eight, and reports the results of the review that has been undertaken. To do this, I use the following headings generated within collating, synthesising and subgroup analysis (steps six and seven), discussed above, to structure this report as follows:
Conversation in Alzheimer’s disease, vascular dementia and Lewy body dementia:

- Early influential studies.
- Work drawing on positioning theory.
- Social and linguistic approaches to conversation.
- Studies specifically using conversation analysis.
- Collaborative storytelling in dementia.
- Formulaic language.
- Conversation as a target for individualised therapy.

Conversation in frontotemporal dementia:

- Conversation in semantic dementia and primary progressive aphasia.
- Conversation in behavioural variant frontotemporal dementia.

Mapping across studies:

- Helpful concepts from the literature.
- Future directions - issues requiring further attention.

2.11 Conversation in Alzheimer’s Disease, Vascular Dementia and Lewy Body Dementia

2.11.1 Early Influential Studies

Whilst early research into communication and dementia had often focussed on pre-determined quantification of problematic communicative behaviours, other researchers interested in conversation began to use alternative methods to record and transcribe more naturalistic conversations, to show that conversation in its everyday context for people with dementia demonstrated different competencies and challenges, from communication so far described in experimental designs or test situations. The work of Hamilton (1994) and Shakespeare (1998) demonstrated rigorous methods of data collection and analysis, with methods adapted from conversation analysis and ethnomethodology.

Hamilton (1994) recorded herself in a care home talking to ‘Elsie’ over a four year period. Extensive data were used to illustrate the decline in Elsie’s ability to
formulate her talk clearly for the listener, e.g. her use of pronouns without a clear reference increased, and her ability to notice and self-repair conversational trouble decreased. As a result, Hamilton had to take on increasing responsibility to facilitate and sustain the conversation. Hamilton also observed that she, herself, did not always indicate when she had not understood Elsie; arguing, in these instances, she chose not to highlight Elsie’s conversational difficulties but instead acted to preserve ‘face’ (Goffman, 1967). Elsie showed relative preservation of the mechanical aspects of turn-taking with more automatic speech, such as linguistic formulas, appearing more resistant to change over time. Hamilton (1994) also showed that Elsie used a variety of positive politeness devices (Brown and Levinson, 1987), including compliments, terms of endearment and jokes, making her an enjoyable conversation partner.

Shakespeare (1998) used audiotaped conversations with people with ‘confusion’ talking in a clinic situation with the researcher and talking at home with family. She distinguishes differences in ability within conversation in her participants, labelling these as ‘minimally active’, ‘moderately active’ and ‘very active’ confused speakers. Shakespeare was interested in how confused speakers were assigned less-than-full-membership in terms of membership categories (Sacks, 1972) and how such issues were displayed in talk. She, for example, describes that ‘ordinary members’ when talking to someone identified with confusion may ‘take license to do some unusual things in conversation – engage in test questions, interrupt, present bizarre formulations and so on’ (Shakespeare, 1998, p.215). Thus the difficulties faced by people with confusion are not only those arising from their cognitive difficulties, but also arising from the actions of others (Shakespeare, 1998).

2.11.2 Work Drawing on Positioning Theory

The beliefs and behaviours of others towards the person with dementia have also been highlighted in other work exploring the social construction of the self and positioning theory. When talking with ‘Dr M’ who had Alzheimer’s disease, Sabat (1991a, 1991b) found it helpful to give her time to organise her thoughts to find words (Sabat, 1991b) and paraphrase and check for understanding using ‘indirect repair’ (Sabat, 1991a). Sabat’s contribution lies in the link he made between the need
for mutual cooperation in conversation in Alzheimer’s disease to the social constructionist work of Harré (1983; 1991), in particular that the communicative scaffolding provided by the conversation partner allows for the social construction and projection of the ‘self’ into social situations (Sabat, 1991a). The ‘self’ is, therefore, a product of joint enterprise, rather than residing in the brain of the individual concerned. Sabat (2001) further explores the relevance of positioning theory (Davies and Harré, 1990; Harré and Van Langenhove, 1999) to interactions with those with Alzheimer’s. ‘Malignant positioning’ occurs when others come to see the person with Alzheimer’s negatively in terms of their deficits alone, rather than their positive attributes and so fail to foster their social abilities, potentially leading to a range of depersonalised interactions (Sabat, 2001).

A more recent study by Purves (2010) draws methods from conversation analysis to analyse positioning in everyday talk at home, in a family where the mother had Alzheimer’s disease. Family members sensitively tried to support the woman’s competence in conversation and negotiate those changes that dementia had brought, e.g. to maintain her role as expert cook, despite others now doing most of the cooking. In this family, depersonalising interactions did not occur, but the author acknowledged each family unit is different with values influenced by different historical and cultural contexts, in this case a Japanese-Canadian context.

2.11.3 Social and Linguistic Approaches to Conversation
Returning to a more linguistic focus, Müller (2003) uses an extract of conversation, taken in a care home with an individual with dementia talking to a researcher, to discuss issues of ‘intersubjectivity’, defined as ‘an interlocutor’s perception that mutual understanding has been achieved’ (p.318). Arguing that intersubjectivity arises from a collaborative system distributed across speakers, Müller describes the various elements potentially at play that extend far beyond the person with dementia’s language competence. These elements include: the linguistic, paralinguistic and nonlinguistic contributions both conversation partners make; contextual elements within the environment, e.g. noise levels, or props available to support cognition, such as a memory book; the knowledge and expectations both conversation partners bring to the situation that shapes their actions; and the online
process of the evolving interaction including both forward planning and backward reflection.

Müller (2003) and Müller and Guendouzi (2005) return to the same theme of mutual understanding, and demonstrate that despite significant problems with memory and fluctuations in intelligibility, skills in conversation were present in the two participants they studied. This included turn-taking and attempts at repair, with responses forthcoming and, whilst topic shifts were abrupt, these contributed to the conversation moving forward. Müller and Guendouzi (2005) argue that different ‘extensions’ of memory are at play in conversation, so for example, memory to hold the perception of an utterance long enough to decode it, turn-exchange length memory for memory within two or three turns, conversation length memory that enables reference to things already established in the conversation and longer term memory referring to events that stretch back over the person’s life. Guendouzi and Müller (2006) use data from four individuals with dementia to illustrate different approaches to study communication in dementia, including conversation analysis, highlighting the strength of interactional data.

Müller and Mok (2014; 2012) examine the conversations between two women with dementia, ‘Ms Beatrice’ and ‘Ms Frances’, living in care and two visiting speech pathology students. Using systemic functional linguistics they demonstrate that the two women with dementia took the most active part in the conversation, using their cultural and social knowledge to attempt to make sense of their visitors within the interaction, despite their memory difficulties. Although the students on one level appeared passive, e.g. tolerating very long pauses in the conversation, their behaviour allowed the women with dementia to take an active part in directing the conversation. In further analysis of this work, Müller and Mok (2014) argue that cognition in dementia is often regarded as a static and context free retention and recall of information (having information), rather than dynamic skills of seeking out and attempting to make sense of the situation at hand, demonstrated in the moments of conversation they studied. They argue, in terms of cognitive skills, the contextually situated ‘doing’ and ‘getting’ has been ignored in favour of the ‘having’.
An expanded view of cognition is also given by Hydén (2014) who provides analysis of two women with dementia cooking with two staff members at a day centre. Extracts from the videotaped activity indicated that, despite significant dementia, the two women played an active part in the activity because of the support provided by the staff. This included: breaking down the activity into manageable steps; appropriate verbal instructions; physical prompting; and the use of objects (and their layout) in the immediate environment. Hydén (2014) argues that, in order to fully understand cognition and communication in dementia, a move away from a focus solely on the person with dementia’s cognitive skills is needed, to one that focuses on other contextual resources, including the cognitive resources of others and physical prompts in the environment: ‘the cognitive and communicative ecosystem’ (p.116).

In another study, Mok and Müller (2013) used systemic functional linguistics to examine casual conversation in a residential facility between five pairs of people with dementia, with the researcher present as a participant observer. Four out of the five pairings produce successful lengthy interactions, lasting between 42-60 minutes, with less hostile interactions than reported in other studies in care homes (e.g. Diaz Moore, 1999). One pairing, however, was unsuccessful, with the interaction curtailed due to repeated communication breakdown and potentially conflicting interaction styles. Both participants engaged in other successful conversations with other residents.

Guendouzi and Pate (2014) used extracts from conversations recorded in a care home with a researcher to demonstrate how ‘F’ (with advanced dementia) used a variety of resources to take part in the conversation: using agreements, minimal responses, formulaic comments and remarks that held general, rather than specific relationships in meaning, to the general schema. They argue there could be alternative explanations for these findings. On the one hand, this represented ‘F’s’ ability to use her retained socially acquired communicative behaviours to compensate for her difficulties. However, an alternative explanation could be that her responses demonstrated an inability to inhibit semantically related information in her thinking and responses. Thus, her conversational behaviour may be the ‘result of an interaction between both cognitive deficits and interactional resources’ (p.142).
Guendouzi and Pate (2014) also discuss the problematic nature of using the word ‘strategy’ to describe such conversation behaviours because of the assumption that this represents a deliberate act, when in all likelihood in ‘F’s’ case, this is non-volitional behaviour.

2.11.4 Studies Specifically Using Conversation Analysis

A number of studies have used conversation analysis, or closely adapted versions of this method, to examine everyday conversations. Kitzinger and Jones (2007) used conversation analysis to demonstrate that ‘May’, a woman with Alzheimer’s, retained many skills whilst making telephone calls to her family. This included routine sequences of call openings including: competent summons-answer sequences (telephone ringing and answering appropriately), recognition of speakers, use of greetings and ‘how are you’ sequences. However, May’s memory problems became evident as calls progressed. Jones (2013) further analyses May’s telephone calls over a two year period. She notes how May’s episodic memory problems led to particular difficulties when her family ask questions relating to recent events, or they attempt to manage her repetitive questions about returning home. May does, however, use her conversation skills to ‘answer without knowing’ and by doing this she was able to answer and take her turn despite being unable to remember the particular information required (Jones, 2013, p.14).

Studies using conversation analysis have explored how people with dementia use laughter within conversation to deal with communication difficulties. Lindholm (2008) videotaped interaction in a day centre and analysed this using conversation analysis to argue that participants’ use of laughter was a compensatory strategy that displayed aspects of competency, i.e. signalling awareness of word finding problems and maintaining the flow of conversation, which preserved identity when managing such conversation difficulties. In another study ‘M’, a man with probable Alzheimer’s disease, was shown to use laughter to demonstrate communicative success after trouble in the conversation and as an instruction to mark parts of his talk as important to the young researcher listening to him (Wilson et al., 2007). This latter aspect also had a function in reinforcing ‘M’s’ identity as an older man giving
advice to one younger and this aspect, along with ‘M’s’ significant linguistic difficulties, are explored further in another publication (Müller and Wilson, 2008).

Chatwin (2014) argues that whilst general issues of interaction have been explored in care homes, micro-interaction analysis is missing from the field and that this detail is required to fully understand the issues at hand and provide appropriate training programmes for staff. He argues for the use of conversation analysis using an extract of conversation from two care workers talking to ‘Ted’ a man with dementia to illustrate how the care workers attempts to reassure Ted, may appear to him as random topic changes, causing misalignment in the conversation between them all.

Jansson and Plejert (2014) used a combination of adapted conversation analysis, together with politeness theory (Brown and Levinson, 1987), to explore the interaction during shower times between three care workers and three residents with dementia. Whilst all the residents protest they do not want their hair to be washed, it is clear from the analysis that two of the workers performed this task in a more step-by-step and negotiated manner, taking account of the residents wishes and discomfort. In contrast, the less successful interactions showed more arguments and threats to ‘face’ were displayed. All conversations were approximately the same length in time, undermining the argument that approaching care in this negotiated manner is more time consuming.

2.11.5 Collaborative Storytelling in Dementia

A small, but overlapping body of literature represents those studies that examine autobiographical narratives in conversation between people with dementia, family and others. Ramanathan (1994; 1995) produced early work highlighting the collaborative nature of narratives in conversation. Ramanathan (1994) illustrates that ‘Tina’, with mild to moderate Alzheimer’s disease, produced extended narratives with the researcher at home; however, in the same activity with her husband, her responses were much shorter. Her husband tended to use event-specific prompts to elicit particular storylines and detail, thus deciding the topic and, at times, talking for her. The researcher took a more passive role and because she did not know the details of Tina’s life, her questions were more open ended and this seemed to allow
Tina to remember events for herself and take a more active part. Ramanathan (1994) argues Tina’s husband had overcompensated for her difficulties, perhaps arising out of a desire to help her maintain such memories. However, when talking to the researcher at the day care centre, Tina was less able to narrate, needing more scaffolding from the researcher within the conversation, with greater evidence of incoherence and egocentricity in her speech (Ramanathan, 1995). It was impossible to draw definitive conclusions in terms of this pattern as only one conversation at home and one conversation at the day centre was compared in this study (Ramanathan, 1995). However, taking the two studies together, this illustrates variability in the skills of the person with dementia in terms of both audience and setting and Ramanathan (1995) argues the need to pay attention to these contextual factors.

Hamilton (2008b) revisits her earlier conversations with Elsie (described earlier in this review) noting that Elsie had more advanced dementia than others described in the literature. Elsie tended not to talk a great deal about the past and of the 204 clauses that did refer to past events, only 27% were part of narratives. The rest were in the form of ‘narrative traces’, or ‘out of the blue’ utterances within talk about the present, that contained past verb tense constructions, indicating this part of talk was about a past event. However, Elsie it was shown, had difficulty creating important anchors of the story-world to help her listener fully understand such narrative traces, e.g. who or what was there in the story, when and where was it and what happened. Hamilton (2008b) argues that whilst a listener might not be sure exactly what is being communicated on a semantic level by an individual with advanced dementia, they may use cues from the talk, nonverbal behaviours and the environment to draw inferences about the narrative traces and, therefore, identity. Hamilton (2008b) uses Bakhtin’s (1981) notion of the ‘flavours’ of words (rather than their specific meaning or functions) and Agha’s (2005) idea of ‘social characterization’ (talk indicating the voice of different speakers) to illustrate that whilst a listener might only have access to a more generic level of meaning from the talk of an individual with advanced Alzheimer’s, they may still be able to reconstruct important aspects of that individual’s identity from this talk; i.e. identity work through talk is still possible at this stage.
Hydén and Orulv (2009) examined instances of a woman, ‘Martha’, with advanced Alzheimer’s disease who lived in a care facility, telling the same story (getting her driving licence), on three different occasions with three different audiences. When telling her friend, ‘Catherine’, who also had dementia, the story had a repetitive quality. With staff, in contrast, there was less repetition because of the way they supported aspects of the story within the conversation. Martha was able to use direct reported speech (the dialogue in the story), paralinguistic features such as tone of voice, gesture and body contact to give the story a dramatizing or performative aspect. Hydén and Orulv (2009) argue that it is not the temporal order, or details of the story that is important but more the moral point or ‘evaluation’ of the story because this illustrates important aspects of identity including a person’s values and norms and at these points listeners particularly joined in. They urge for more study of performed and embodied identity in dementia.

Hydén et al. (2012) return to this data to illustrate the active and attentive part that Catherine, Martha’s friend, plays within the storytelling interaction, using continuers (‘mmm’, ‘yeah’), news-marks (‘you don’t say!’) and formulations (summing up the gist of what has been said or requesting a clarification). However, she does not indicate she has heard this story before, either in her talk or her intonation. The two women are actively engaged in this socially rewarding encounter, despite the repetition and the story often lacking a temporal structure. It appears that the activity of storytelling is more important than the details of the story for them.

Hydén (2013; 2011) demonstrates that conversational storytelling is a collaborative activity in dementia, with family carers providing ‘narrative scaffolding’ to help the person with dementia tell their story. Remembering together, for ‘Oswald’, a man with dementia and ‘Linda’, his wife, was a way to support their identity as a couple, rooted in their long term commitment to each other (Hydén, 2011). Hydén (2013) additionally demonstrates the embodied nature of the storytelling, for example how Oswald used gestures to convey parts of the story, because his linguistic and memory difficulties made it hard for him to use verbal means. Hydén (2013) makes the case for video recording and analysis to be a standard methodology when researching narrative activities, in order to pick up such embodied behaviour.
Davis and Maclagan (2014) examined an extensive longitudinal corpus of conversation with ‘Maureen Littlejohn’, a woman with dementia living in care, talking to students and researchers. Whilst from a single conversation it would be difficult to see any issues with Maureen’s talk, analysis over time indicated Maureen’s favourite stories seemed to be slipping into the conversation more and, in later data sets, were repeated within the same conversation. These were not pure perseverations, as the format and details changed a little each time. Analysis revealed that listener feedback was important to encourage Maureen to keep talking, particularly the use of emotive/evaluative responses, e.g. ‘that’s good’. Formulaic language and extenders, e.g. ‘and stuff like that’, were used by Maureen and appeared important to help her take part in conversation.

2.11.6 Formulaic Language

There is also other literature that further examines the use of formulaic language in those with dementia within conversation. Such formulaic sequences have been defined as: ‘a sequence, continuous or discontinuous, of words or other meaning elements, which is or appears to be, prefabricated: that is, stored and retrieved whole from memory at the time of use, rather than being subject to generation of analysis by the language grammar’ (Wray, 1999 p.214). A number of authors have raised the importance of this for people with dementia, e.g. just discussed for Maureen above (Davis and Maclagan, 2014) and ‘ready-made language’ was noted in Elsie’s conversations (Hamilton, 1994). Guendouzi and Müller (2001) noted that certain well used phrases frequently cropped up in conversations with ‘F’, a woman with dementia and, in contrast to other talk, these sequences stood out because of their greater intelligibility.

Wray (2010) observed ‘Joan’, a renowned opera singer now living with dementia, delivering a weekend singing workshop. For Joan, the workshop format was highly familiar so she understood the requirements of the task; success was also attributed to her retained musical skills, ability to use gesture to convey ideas, the sensitive support from her co-trainer and her use of formulaic utterances, which were appropriate in this context. Wray (2014) argues that formulaic language is used in normal conversation and when processing demands rise, such prefabricated
sequences can be relied upon to increase capacity for production and comprehension. In Alzheimer’s disease reduced cognitive processing can lead to an increase reliance on such formulaic sequences (Wray, 2014).

2.11.7 Conversation as a Target for Individualised Therapy

Therapy targeting conversation has been used in aphasia following stroke for a number of years (see Simmons-Mackie et al., 2014, for a review of this area), but has received less attention in dementia care. Perkins et al. (1997) audiotaped and analysed conversations between individuals with Alzheimer’s disease and Lewy body dementia in conversation at home with their family carers (without researchers present) and, from this, developed a clinical resource to examine interaction: ‘Conversation Analysis Profile for People with Cognitive Impairments (CAPPCI)’. This was followed by an influential paper arguing that conversation analysis is well placed to contribute to dementia care because it has high validity for therapeutic interventions as it provides analysis at the level that intervention is ultimately targeting: everyday talk (Perkins et al., 1998). The authors emphasise the collaborative nature of conversation and that a person’s ability to produce meaningful talk is not just a function of cognitive ability but also interactionally produced. Analysis of conversation, therefore, gives a profile of skills and difficulties that can be used to derive individually targeted education and advice. Perkins et al. (1998) present data to illustrate a range of issues, such as as allowing time to respond in turn taking, different approaches to repair and their associated consequences (e.g. pursuing a repair or ‘passing over it’, p.43) and the challenges in managing topics and topic shifts due to memory difficulties in dementia.

Interviews in the CAPPCI explore carers’ perceptions of conversation difficulties alongside their strategies used to manage them (Perkins et al., 1997). A later publication examined this further in Lewy body dementia, categorising family carer strategies as: facilitatory, confrontational, acceptance, avoidance and emotive responses, arguing that acceptance and coming to terms with conversation difficulties, were an important aspect to carer coping (Whitworth et al., 1999). The CAPPCI contains a carer interview but no interview with the person with dementia, perhaps reflecting the focus on carer experience prevalent at the time. This clinical
resourse has not been systematically evaluated and, so far, has not been extensively used in clinical practice.

Conversation analysis may have potential to be combined with other successful therapy strategies, such as the study discussed in the introduction by Spilkin and Bethlehem (2003). Here conversation analysis was used to analyse interaction between a man with dementia and his daughter using a memory book made by the researcher. An individualised training session took place aiming to enhance the quality of this interaction using strategies derived from the analysis. Following training, conversation analysis was again used to explore the effects of intervention. This showed the conversation flowed more smoothly with greater involvement of the man with dementia and more topics were explored in depth. The authors concluded that individualised advice around use of memory aids was required, particularly as the format may encourage labelling and listing of information.

2.12 Conversation in Frontotemporal Dementia

2.12.1 Conversation in Primary Progressive Aphasia

The literature search revealed only one study examining everyday conversation in semantic dementia (Kindell et al., 2013). This study described how ‘Doug’, a man with semantic dementia, had a repeated practice of acting out scenes (referred to as enactment) within conversation using direct reported speech, changes in vocal pitch and loudness, body posture and facial expression. It was argued that this practice was supported by skills with autobiographical knowledge and visuospatial function. This enabled Doug to take part in conversation and the listener to gain, at least some meaning from him, despite significant linguistic difficulties. Doug’s wife Karina spoke about her ability to get ‘the general gist of what’s going on’ (Kindell et al., 2013, p.506) and the need to prioritise the flow of the interaction, as much as the information content.

Kindell et al. (2013) drew on earlier work by Simmons-Mackie and Damico (1997) who videotaped two women at home and at the clinic, one (referred to as ‘N.N.’) experiencing non-fluent primary progressive aphasia, in order to study compensatory
strategies. By studying the videotapes alongside other ethnographic data, Simmons-Mackie and Damico used a qualitative cycle of analysis, coding and further data collection and coding in order to refine their definition of compensatory behaviours. This generated a description for the 2742 instances of compensatory strategies they collated from the eight hours and 30 minutes of video recording. Compensatory strategies were re-defined as ‘a new or expanded communicative behaviour, often spontaneously acquired and systematically employed, to overcome a communication barrier in an effort to meet both transactional and interactional communicative goals’ (Simmons-Mackie and Damico, 1997, p.770). For example, N. N. had a word book she had been taught to use, regarded as a traditional compensatory strategy, but she also used other less conscious practices including gestures to convey meaning and emotion or regulate the conversation flow, or words such as ‘nice,’ ‘really’ and ‘wonderful’ to take a turn, but then shift the burden of conversation back to the other speaker. This definition moves away from compensations seen solely as consciously learnt practices, to include those spontaneously acquired over time, such as doing more of something, e.g. gestures, or using the skills the individual has available in new ways.

The search revealed only one other study examining conversation in primary progressive aphasia. In terms of design, this study is technically outside the criteria for this literature review because a pre-defined set of codes were used to collate and quantify data and conversations took place in a clinic setting. However, I have pragmatically chosen to include it here because of the lack of literature in this area and because conversation extracts discussed in the paper provide some useful information, alongside the quantitative data. Taylor et al. (2014) used the coding scheme developed by Watson et al. (1999), to examine sources of trouble and types of repair strategy in video recorded conversations with three women with non-fluent or logopenic primary progressive aphasia, compared to control couples. Overall the study found that whilst the women experienced language difficulties and produced less talk, they were able to turn take and contribute to the conversation. Patterns of trouble and repair were unique to each couple and were not associated with progressive aphasia type, as had been hypothesised. For example, ‘Tina’s’ friend (her ex-husband) was noted to use cues, prompts or ‘test questions’ (questions where the answer was already known) to elicit a desired response and this was generally not
helpful. In contrast, Tina’s requests for her partner to suggest a word, she was struggling to find, was helpful and effectively moved the conversation forward. The authors make a recommendation for individually tailored communication advice based on analysis of sources of trouble and repair for those living with these conditions.

2.12.2 Conversation in Behavioural Variant Frontotemporal Dementia

With respect to behavioural variant frontotemporal dementia, all the studies located arose from work undertaken in Los Angeles, USA, by the Social Relations in Frontotemporal Dementia Research Group. This is collaboration between researchers in the social sciences (applied linguistics and social anthropology) and a neurological centre. This research group aimed to use conversation analysis and ethnography, focusing on data gathered in naturally occurring settings to study interaction and behaviour. A strength of this group’s work is that large amounts of video and audio data were gathered from conversations at home and during activities in the community. This encompasses the work of Mikesell and colleagues including a book from this group (Joaquin, 2010a; Joaquin, 2010b; Mates et al., 2010; Mikesell, 2009a; Mikesell, 2010a; Mikesell, 2010b; Mikesell, 2014; Smith, 2010; Torrisi, 2010). Within this body of work authors often mention the importance of their mixed methods approach. For example, Torrisi (2010) discusses how participant observation over an extended period of time and, in different contexts, helped guide which aspects of interaction to explore more fully through conversation analysis. Mikesell (2009) notes the natural variability of all conversation and outlines the need to be mindful of the frequency of behaviours under scrutiny and provide a detailed analysis of each instance, including the reaction of others. Thus, a given behaviour is not judged after the event by the analyst as appropriate, problematic etc., but is analysed in-situ including examining how co-participants treat that behaviour in context at the time.

Further examination revealed that one participant from this group’s work, ‘Kelly’, described as having frontotemporal dementia, also had a prior diagnosis of semantic dementia, although the language disorder was reported not to be particularly
problematic in ordinary interactions (Mikesell, 2010a). Kelly was described as egocentric in conversation, with a lack of impulse control and perseverative conversation (particularly checking her medication) (Mikesell, 2010a; Torrisi, 2010). In addition, it was argued that within conversation Kelly showed a ‘breakdown in social regulation’ (Torrisi 2010, p.28) with a tendency to turn topics to herself rather than the orientation of her conversation partner and she showed a lack of expected verbal, embodied and emotional reactions within situations, compared to those around her. Carers used a variety of strategies to manage Kelly’s perseverative responses including: reasoning over behaviours, distraction (e.g. changing the topic of conversation) or physically guiding Kelly to more appropriate body responses (e.g. her physical orientation to the situation and others). Mikesell (2010a) reports that whilst both the ethnographer and Kelly’s husband used distraction when reasoning was not successful, her husband was quicker to move through this sequence, perhaps reflecting his greater familiarity with her needs.

With respect to behavioural variant frontotemporal dementia, Mikesell (2009) analysed the conversation of ‘SD’, a man in his 70’s described as exhibiting the ‘apathetic variant of frontotemporal dementia’ (p.138). SD was shown to have few problems with isolated question and answer turns, with his answers often conforming to grammatical expectations and on the surface these sequences looked much like normal conversation. In contrast, extended sequences were particularly problematic with recurring features, including difficulties with initiation and elaboration of topics and frequent use of ‘minimal responses’, e.g. ‘mm’ and ‘I don’t know’ which, when placed within the larger sequences, could be inappropriate or contradictory. Mikesell notes how those talking to SD ‘work to provide scaffolding’ (Mikesell, 2009a, p.159) to include and sustain his involvement, such as narrowing questions when a lack of information was forthcoming, with ‘yes/no’ questions forming an important aspect to this.

In examining repetitional responses, Mikesell (2010b) argues that, despite the often used description of ‘echolalia’ in behavioural variant frontotemporal dementia, the responses provided by ‘Steve’ and ‘Romeo’, were not meaningless repetitions but had a function in the conversation allowing the individual to participate and respond within the conversation. In some instances, the repeat was modulated in some way
and this, along with their embodied response, indicated the person’s awareness that, for example, they were being directed like a child. Given that people with frontotemporal dementia are potentially faced with a greater proportion of directives (to initiate and regulate behaviour), Mikesell (2010b) argues that the high rate of repetition in their speech may arise, not solely out of changes in the brain, but this may also reflect the context of care.

Returning to her original data, Mikesell (2014) used the work of Sacks (1992) to examine how understanding was demonstrated with different levels of evidence within the interaction of three participants with frontotemporal dementia: ‘Steve’, ‘Romeo’ and ‘Kelly’. She showed that ‘claims’ might merely acknowledge the previous turn, by, for example, repeating information within it. ‘Displays’ show greater evidence of understanding by providing additional information, such as reformulating the information in an utterance, or other response indicating interpretation of the prior turn. In her terminology ‘demonstrations’ were reserved for instances where an action or physical response was required to demonstrate understanding, generally during a joint activity. Mikesell (2014) illustrates instances where individuals seemed to understand by using claims or displays, but when required to demonstrate understanding, by an embodied response, this was not forthcoming. Much like her earlier work with expression, Mikesell demonstrates that the issue is not so much with turn by turn understanding but with understanding the ‘over-arching agenda of the entire sequence’ (p.173) and it is at this level that the cognitive planning and integration breaks down.

Joaquin (2010a) demonstrates how certain interactional features (directives, ‘let’s/we’ framed sequences, initiation-response-evaluation sequences) used to guide the behaviour of the person with behavioural variant frontotemporal dementia, were like parent-child interactions. Such verbal assistance led to a diminished status, despite evidence in some cases that competency was missed and therefore this assistance was not always necessary. In another publication, Joaquin (2010b) argues that the social rules learnt from childhood through to early adulthood, become lost in frontotemporal dementia, arising out of damage to the prefrontal cortex.
Smith (2010) discusses the labels often applied to people with frontotemporal dementia, e.g. ‘embarrassing’, ‘indifferent’, ‘self-centred’ noting that ‘the morality of these descriptions remains something endemic to frontotemporal dementia’ (p.50). Such labels may be perceived as not arising out of a lack of ability, as might be the case with memory failure in Alzheimer’s disease, but perceived as ‘a lack of willingness whereby they lack the moral constitution to enact moral, or resist immoral, actions’ (p.76). Arguing for a need to study the complexities of behaviours in-situ, Smith presents conversation from ‘Louise’ (with behavioural variant frontotemporal dementia) and ‘Vera’ (another individual with frontotemporal dementia and semantic dementia) talking to family, researchers and strangers. Conversation partners were shown to facilitate and normalise any issues within the interaction, e.g. deliberately bringing Louise and Vera into the conversation; rephrasing their talk to help understanding; and if it involved inappropriate remarks to a third party (in this data to strangers in a shop), conversation partners worked to smooth over this breach, thus normalising it before moving the conversation forward and away from the current order. With respect to displays of emotion, Vera demonstrated care for her family (carefully choosing and wrapping gifts for Christmas) and within conversation showed instances of empathy towards the ethnographer, with some insight into changes in her behaviour. However, Vera’s interaction style could sometimes appear insensitive, often arising from her tendency to move the topic on to herself within the conversation. Smith (2010) notes the ‘person-specific bias’ (p.65) in his participant’s talk and he argues that some of the behaviours that appear on the surface as self-centred, might be due to participants relying on this personal knowledge to engage in action, simply because they no longer have access to other forms of experience.

2.13 Mapping across Studies
These studies illustrate that conversation data are a rich source of information for research and practice, illustrating in detail both the challenges and skills of people with dementia within everyday communication. The collaborative nature of everyday conversation is demonstrated and in terms of support, it is clear that the behaviour of others can scaffold, not just the conversation abilities of the person with dementia, but in turn support their well-being and identity. However, mapping results across
studies can be difficult due to variability in methods used, and differing emphases from linguistic, psychological and sociological perspectives. In addition, the conversation practices discussed in this review are diverse. There are also methodological challenges with generalisation from qualitative case study work. The nature of the contextualised experiences presented within these studies makes it unhelpful to overly generalise, for example, a checklist of helpful and unhelpful communication practices would be inappropriate. More in keeping with the philosophical and methodological underpinnings of these studies, is to draw together useful concepts for dementia practitioners and researchers followed by discussion of potential gaps in the literature. I will then discuss the relevance of these findings to my own study.

2.13.1 Helpful concepts from the literature

**Transaction and Interaction:** All of the studies in this review present a broader view of communication than is currently presented in the biomedical literature or general discussions of communication in dementia. The biomedical literature tends to focus on an individual’s ability to convey information, largely in test situations such as when naming or describing pictures. Illustrated by Simmons-Mackie and Damico (1997) the goal of conversation, however, is not solely to convey meaning, or transaction, conversation also has an important interactive function. This division into transaction and interaction is a particularly useful concept for those working with people with dementia in the more advanced stages, who appear to retain many skills with interaction, even when their ability with transaction is declining.

**Display of Abilities in Conversation:** A number of the studies in this review illustrate that people with dementia may draw on retained abilities in order to take part in conversation. For example, in spite of significant cognitive challenges, skills can be seen with turn-taking (Hamilton, 1994; Mikesell, 2009a), routine sequences (Kitzinger and Jones, 2007), enactment (Kindell et al., 2013), attempts at repair (Müller and Guendouzi, 2005), attempts to make sense of other speakers (Müller and Mok, 2012; Müller and Mok, 2014), the use of laughter to display competency
(Lindholm, 2008; Wilson et al., 2007) and the use of formulaic language (Davis and Maclagan, 2014; Hamilton, 1994; Wray, 2010).

It is common in clinical practice to have differences of opinion between members of the team or between staff and family carers, regarding a particular individual’s communication skills. The conversation literature provides a number of perspectives to unpick such differences. For example, those focussing on ‘transaction’ may feel that the difficulty a person with dementia has in giving specific information at a given time, means the person cannot communicate effectively. In contrast, others focussing on interactional abilities may see the skills behind the words, e.g. turn taking, eye contact, laughter, and feel that the individual effectively communicates in other ways. In terms of practice, this delivers important vocabulary to describe how connecting with people with dementia does not have to rest solely upon the transfer of information and how in terms of support, activities and care, focussing on interactive abilities is an important focus for social connections.

**Recurring Patterns of Abilities - A Strategy?** Whilst some authors have used the word ‘strategy’ to reflect certain recurring positive conversation practices used by people with dementia (Jones, 2013; Kindell et al., 2013; Lindholm, 2008; Simmons-Mackie and Damico, 1997), albeit with a reworked definition, others have questioned whether ‘strategy’ is the right term given the assumption that this represents volitional and deliberate behaviour (Guendouzi and Pate, 2014). Such behaviours may be described as strategies, practices, techniques, compensations or adaptations; noticing and actively facilitating these unique behaviours lies at the heart of person centred practice. It is argued that such behaviours are likely to be highly individualised and, both assessment and therapy, will be more fruitful if it begins with understanding an individual’s current strategies and builds on those (Kindell et al., 2013; Simmons-Mackie and Damico, 1997).

**Cognition Viewed as Dynamic and Co-Constructed:** The studies reviewed here deliver a dynamic and co-constructed representation of cognition that might appeal to those seeking to facilitate skills through provision of appropriate support. Particularly interesting is Müller and Mok’s (2014) attempt to place cognition in an everyday context, thus moving away from ‘having’ information, say in a
decontextualized test situation, to ‘dynamic seeking out of learning and joint construction of understanding’ (p.80) the ‘doing’ and ‘getting’ of cognition. In addition, the notion of the cognitive and communicative ecosystem discussed by Hydén (2014) gives practitioners a way to consider how cues to thought, communication and action are distributed not just in the communication of others but also in the physical environment.

There are parallels in the work of Smith (2010), Mikesell (2010b) and Joaquin (2010a) who demonstrate the potential that conversation analysis has to uncover the perspective of the person with frontotemporal dementia, including situated displays of interpersonal awareness. This presents an interesting way to explore issues such as awareness, insight and identity, for those with frontotemporal dementia and more advanced dementia of any kind. This may represent a move away from discussions of ‘having awareness’, in a decontextualized sense, to the situated display or ‘doing of awareness’.

**The Complexity of Cognition in Conversation:** The conversation literature also displays the complexities of cognition in conversation and the integration of multiple cognitive domains (language, memory, executive function etc.). A range of cognitive processes and functions are discussed in these studies, for example: word finding (Taylor et al., 2014), semantics (Guendouzi and Pate, 2014; Kindell et al., 2013), episodic memory (Jones, 2013), short and long term memory (Müller and Guendouzi, 2005), articulation and prosody (Whitworth et al., 1999) and executive function (Mikesell, 2009a). Mikesell (2009; 2014) illustrates, with respect to both expression and reception, for people with frontotemporal dementia everyday interaction makes multiple cognitive demands across turns, across whole sequences and indeed from one sequence to another. A similar notion is also evident in the work of Müller and Guendouzi (2005) in their discussion of memory in conversation, including that required within the conversation to memories extending back over the life course.

**Maintaining Face in Conversation:** Whilst conversation may display skills not observed on cognitive testing, the literature also illustrates how exposing conversation can be for people with dementia, particularly talk of a less supportive
nature. Practitioners working with individuals living with early dementia often hear the person describe how their difficulties with conversation cause anxiety, fear and even avoidance of social situations. Likewise, relatives ask if they should correct the person when errors arise or mark if they have not understood for fear this may upset them. A number of authors have discussed such issues, relating this to the work of Goffman on ‘face’ (Goffman, 1967) and Brown and Levinson’s discussion of principles of politeness in conversation (Brown and Levinson, 1987). Hamilton (1994) reports how she did not always highlight Elsie’s difficulties, choosing to let these go to preserve face. Perkins et al (1998) argue that repair is a delicate business for family carers as exposing memory failure can be seen as a face-threatening act. Guendouzi and Pate (2014) discuss such theories with relation to dementia, including the way in conversation speakers chose their words to ‘attend to the psychosocial dimensions of interpersonal communication’ (p.124).

Conversation analysis provides a useful way to explore such issues and the description of these as ‘trouble sources’ rather than ‘errors’ gives a framework to shift the focus from the person with dementia to a more collaborative approach that considers not only the conveyance of meaning but psychosocial dimensions (Perkins et al., 1998). Taylor et al. (2014) notes that participant ‘Tina’, with primary progressive aphasia, actively asked for words when trouble arose, therefore, self-initiating the repair that her partner provided. Self-initiated and other-initiated repair and subsequently, whether ‘self’ or ‘other’ then completes this repair might initially appear as complex detail for practitioners. However, this does provide a useful framework for considering the nature of the trouble source, who signalled it and for what purpose, whether this was done in an indirect or direct manner etc. and then, who effectively repaired the trouble. Finally, the consequences for how this was managed to both the information conveyed and the person with dementia’s face can be considered.

2.13.2 Future Directions - Issues Requiring Further Attention

A Nuanced and Contextualised View of Communication: The conversation literature illustrates a very real challenge in the delivery of communication support
and training in dementia care: the huge variability in communication skills and difficulties across individuals with dementia, the different types of dementia, from the earliest to the advanced stages of these conditions and the different support structures around the individual. This may explain some of the issues that on the surface appear contradictory. For example, Mikesell (2009) illustrates that when a lack of information was forthcoming; ‘yes/no’ questions were important to encourage the person to engage. However, Ramanathan (1994) argues that open ended questions were important to allow the person with dementia to take a more active part in the conversation. Whilst there may be general principles of communication in dementia care, particular conversation practices and strategies may also be highly individualised. As discussed within Chapter 1, training programmes around communication often provide generic advice and lack information or procedures for tailoring such advice to individual need (Young et al., 2011) and this tension between generic advice and individual communication need requires further attention in research and practice.

Relating Findings to the General Dementia Literature and Practice: The conversation literature acknowledges the cognitive changes present in dementia but moves beyond this to examine the psycho-social context. This is very much in keeping with a bio-psycho-social approach to dementia care, often promoted as good practice (Sabat, 2008). Despite the obvious parallels, few studies have made links to the broader dementia care literature in terms of approaches used, models or philosophical underpinnings, apart from the occasional mention of the work of Kitwood (1997). For example, whilst Mikesell and her colleagues make many linkages in their work with basic neuroscience and the functioning of the brain in frontotemporal dementia, there are very few references to the psychosocial dementia literature, despite the potential for this to occur. In addition, whilst many studies recommend their methods for further research, individualised assessment or to generate appropriate training for carers, concrete clinical applications are hard to come by and at times the literature appears to lie in parallel rather than inform practice.

In some instances there are potential points of conflict with current therapeutic approaches. The work on co-construction of conversational narratives has much to
inform life story approaches in dementia care. For example, Hydén and Orulv (2009) argue it is the moral point of the lived life that is important, found in the performance of co-constructed narrative, rather than remembering important ‘facts’ about oneself, e.g. marriage, children etc. However, in life story work carried out in clinical practice, the use of certain tools to explore life stories, may pay attention to exactly this factual information, rather than the performance of the narrative (Kindell et al., 2014a).

**Unpicking Memory and Other Cognitive Skills:** In terms of memory, Jones (2013) observed how questions about recent events were particularly difficult for May to answer; whilst Müller and Guendouzi (2005) break down memory into those memories relating to the immediate conversation and other memories extend back over the life course. However, whilst differences between immediate memory, recent memory and long term memory inform differential diagnosis (Snowden, 2010) and are brought to the fore in interventions such as reminiscence therapy and life story work, this review did not find any systematic attention to how difficulties with different types of memory affect conversation. In particular, the notion of immediate memory or short term memory difficulties affecting such within conversation abilities such as keeping track of the talk of self and others is less explored. Given the different reported profile of long term memory in frontotemporal dementia and in particular in semantic dementia, there is also no literature examining whether conversations about recent or long terms events differ in any way in such conditions.

**Cognitive or Social or Both?** Within the literature some authors focus on more social explanations whereas others relate their finds more to issues with cognition, in part affected by the approach they take. Antaki (2011) describes different types of ‘applied conversation analysis’ along with some of the tensions that arise in the initial stance researchers may take. Antaki (2011) describes the work of the Social Relations in Frontotemporal Dementia Research Group, reported in Mates et al. (2010) as ‘diagnostic applied conversation analysis: correlating sequential features of talk with clinical disorders’ (p.6), i.e. exploring how the clinical features of frontotemporal dementia manifest within interaction. This is particularly evident in reports where conversation data are presented alongside brain scans and discussion of underlying pathology (e.g. Torrisi, 2010). In contrast, other researchers do not
provide data on the underlying cognitive function and even in some instances diagnosis is not clear (e.g. Wray 2010; Shakespeare 1998), with the focus of study examining social aspects.

Guendouzi and Pate (2014) raise the problematic issue of focussing on either cognitive or socially driven theories when both aspects may be necessary to account for particular behaviours. In their data, ‘F’ had many retained social behaviours, yet psycholinguistic theories were also able to explain some of the phenomena, so her behaviour could be the result of an ‘interaction between intact learned social behaviours and faulty or inaccurate cognitive systems’ (Guendouzi and Pate, 2014, p.143). In terms of research, they note the division between psycholinguistic and qualitative approaches, arguing for models of language and cognition to take account of real world data and for qualitative researchers to also consider cognitively driven explanations in their analysis. Likewise, Hamilton (2008a) advocates for the need to bridge the gap between sociological/anthropological perspectives and psycholinguistic/neurolinguistic ones. This tension between cognitive and social dimensions is one recognised by many practitioners and is where a bio-psycho-social framework recognises multiple and interacting issues are at play simultaneously (Sabat, 2008).

**Exploring the Perspectives of Family Carers:** Studies specifically exploring face to face everyday conversation between people with dementia and their family carers at home, without researchers present, are surprisingly rare (e.g. Perkins et al., 1998; Purves, 2010; Whitworth et al., 1999). Communication problems have been linked to carer burden (Savundranayagam et al., 2008) and it is rarely acknowledged that family carers may have their own needs, or agenda, within an interaction beyond facilitating the person with dementia’s communication. In some studies both family carer and researcher interaction is present in the data and there are hints that there may be some differences. Mikesell (2010a) notes that whilst similar strategies are used to manage Kelly’s perseverative topics, her husband Bron is quicker to move from reasoning, or explanation, to distraction, than the ethnographer. Smith (2010) illustrates that in some instances family carers showed irritation or frustration during interactions. He briefly explores issues such as ‘investment’ in the interaction (e.g. getting a memory ‘correct’) or having a third party present to support the situation,
but does not explore such issues in depth. It seems probable that, for example, a breach in the conversational order, such as an inappropriate comment to a stranger, is likely to be felt very differently by a daughter, as opposed to a paid carer or a researcher in that situation and this may, in turn, affect the interaction.

Many conversations for research purposes involve conversation with no goal other than to gain a language sample or engage the person with dementia in interaction. This may require different demands to everyday life situations that emphasise transaction to a greater degree. For example, Brewer (2005) (not contained in the literature review), a family carer, reported conversations with her own mother-in-law illustrating that for families the need to convey, and retain information may be very important; here helping the woman to retain that her husband had died, the family fearing a sudden period of lucidity during the funeral leading to acute upset. Jansson and Plejert (2014) illustrate a similar issue for care workers in residential care carrying out care activities. They argue that whilst care work is seen as ‘simple labor’, the complexity of the interactional skills required in order to facilitate resident’s cooperation, in this case with showering, calls this into question. Whilst researchers may be able to ‘go with the flow’ to produce a conversation sample, family carers, or care workers, however, may have an agenda of daily life to get through and this may place their interactions differently.

Lastly, there is also evidence from the qualitative dementia literature that couples may have different ways of ‘working’ or being a couple in the face of dementia (Hellström et al., 2007; Keady and Nolan, 2003; La Fontaine and Oyebode, 2014) and this may influence interaction. Overall, therefore, there is a need to directly examine interactions between the person with dementia and their family carers, particularly for therapeutic aims, and examine how this sits within the broader context of their lives and their relationships.

**Illuminating Everyday Dilemmas and Complexity:** Providing support to both people with dementia and their relatives is at the heart of community dementia practice, however, this is not without its challenges. Other qualitative research has highlighted that tensions may exist between the needs of the spouse and the person with dementia (O’Connor, 2007; O'Shaughnessy et al., 2010). Conversations are also
likely to reveal such tensions, for example, whilst a person with dementia may be unaware of repetition in their talk and may be upset when this is pointed out, a family carer living with such behaviours continuously, might find it hard to achieve a calm response. It would seem that conversation based research, and particularly conversation analysis, has the potential to explore the perspectives of all concerned in a non-judgemental manner and to tease out the complexities and dilemmas within such situated experiences. However, it appears that the literature has yet to fully exploit this potential. In addition, investigating how such issues evolve on a longitudinal basis would seem a logical methodological development.

Wray (2014) provides an interesting analysis of this nature in her discussion of the dilemma faced by family carers in their response to increasing use of formulaic language in dementia. She argues that if carers assume this increase represents normal language then the consequence might be to view the person as rude, not listening etc. However, to treat the language as abnormal ‘is to challenge the person’s capacity to behave like a human being and this might change the ground rules for how the person is treated’ (Wray, 2014, p.279). Wray (2014) goes on to argue for empathy-training that helps carers to see what functions the formulaic language is having for the person with dementia. Shakespeare (1998) also discusses some of these issues with respect to different carer strategies for repair of confused talk, in that certain ways of responding, even those which are helpful, orientate to less-than-full-membership because, in normal conversation, such practices typically do not occur.

**Goals for Therapy:** There appear to be different challenges in describing conversation practices to those aiming to change conversation practices through therapy and whether the latter in particular requires engaging with psychological states and speaker intentions, a practice avoided in pure conversation analysis (Torrisi, 2010). This is the case in aphasia practice where psychosocial aspects are often addressed alongside conversation therapy (Lock et al., 2001). Such approaches to therapy, whilst often advocated, remain untested in dementia care. Given the complexity of the condition for both the person with dementia and their family, it would appear that whilst understanding the psychological backstory might not be
necessary to describe conversation practices, it may be necessary when attempting to change conversation practices in therapy.

**Ethics:** Despite the ethical complexity of many of these studies (e.g. capacity to consent, observation and recording in various settings) there is often a lack of discussion of ethics. Relatively few studies state that prior informed or written consent was given by the person with dementia, although informal consent to record talking at the time is often noted. Relatives are often quoted as giving ‘proxy consent’. This may simply represent issues with reporting, or differences in procedures for consent in earlier studies, but it is interesting when comparing this literature and other qualitative literature in dementia, that the latter tends to address this issue more overtly than the conversation literature. This also seems at odds with the empowerment movement in dementia, encouraging people with dementia to talk for themselves rather than through carers, for example, as illustrated through the Dementia Empowerment and Engagement Project (Mental Health Foundation, 2014).

There is also the issue of different ethical procedures in different countries. In England and Wales there has been a clarification of requirements under the Mental Capacity Act (2005) in this area with more explicit guidance in 2011 stating that any research involving those who lack capacity to consent for themselves must be agreed by certain approved health and social care ethics committees, rather than by university ethics committees. The rigorous procedures of such committees make certain research practices with individuals with dementia who lack capacity more challenging to deliver. For example, recording intimate self-care tasks as Jansson and Plejert (2014) did in Sweden, or using roving video recording in public, as Smith (2010) used in the USA, would require a great deal of attention to ethical detail to deliver in England and Wales.

**2.14 Summary and Implications for this Study**

The conversation literature reveals a number of important concepts for dementia care although these findings have not always been translated into recommendations for clinical practice. Overall, the literature review revealed that very few studies have
examined face to face everyday conversation at home between people with dementia and their family carers, without researchers present (Perkins et al., 1998; Purves, 2010; Whitworth et al., 1999). Given the prominent place communication holds within person centred dementia care practices and the importance of facilitating communication between the person with dementia and their family this appears remarkable. Study of interaction in frontotemporal dementia is a relatively new field and, so far, the focus has largely been on behavioural variant frontotemporal dementia, with literature exploring conversation in semantic dementia and primary progressive aphasia, particularly sparse. Studies in frontotemporal dementia have demonstrated the potential of mixed methods approaches; however, particular exploration of the conversation of family carers is needed.

Aiming to effect changes in interaction at home in dementia, using conversation therapies, has not been explored. This is despite numerous researchers stating the clinical implications of their work are that effective individualised advice for people living with dementia and their family carers is required to foster effective conversations. The co-construction of identity through talk and in particular through fostering narratives about the self in conversation is threaded throughout the conversation literature in dementia. However, it remains unclear as to how such issues should be addressed within therapy aiming to improve conversations at home. Life story work, for example, has been identified as offering potential to fostering conversations in dementia (Spilkin and Bethlehem, 2003) but it has been argued that the research literature remains exploratory (McKeown et al., 2006) and requires particular attention to aspects of interaction (Hydén and Orulv, 2009; Kindell et al., 2014a).

This review, therefore, indicates that the study of conversation in semantic dementia and potential interventions to support conversation at home with family carers presents as an area worthy of further research. It also suggests a variety of methodological tools to focus on such natural conversations. In the next chapter I will illustrate how the findings from this literature review have been used to situate and frame this particular research project.
CHAPTER 3

Methods of Study

3.1 Introduction
This chapter describes the methodology and methods used in the study. Firstly, the theoretical rationale and the aims of the study will be outlined along with the reasons for moving from a case series design to a multiple case study design. Reflexivity and issues of ‘practitioner research’ within the thesis will be addressed. The study design will be described with an overview of conversation analysis and narrative analysis and the reason for using the two methods together for assessment, as well as in an intervention design, using interaction-focussed therapy and life story work. The chapter will then move on to describe how rigour was addressed in the research process. Lastly, the complex ethical issues inherent in the study, sample size and issues of recruitment are discussed.

3.2 Theoretical Rationale for Study
As I have illustrated in the first two chapters, there are potentially a number of ways to study communication issues in semantic dementia, although currently there is only one published study examining everyday conversation at home (Kindell et al., 2013). As the substantive literature review in Chapter 2 demonstrated, conversation is an everyday, contextualised and co-constructed behaviour and research from this perspective has provided a much broader and richer understanding of natural communication in other forms of dementia, including behavioural variant frontotemporal dementia. However, whilst this approach offers potential to deliver individualised interventions around communication, as yet this knowledge has not been effectively translated into advice about interaction to help those living with dementia, including semantic dementia, and their families. The bio-psycho-social model has made very little impact on the literature on frontotemporal dementia, although the model appears to offer a great deal to conditions where the juxtaposition of abilities and disabilities are striking (Kumamoto et al., 2004).
This thesis presents as an early attempt to design and explore interventions to enhance interaction at home in semantic dementia and therefore builds on work within aphasia therapy and dementia; in particular, previous work examining interaction-focused therapy in aphasia (Lock et al., 2001; Wilkinson et al., 2011; Wilkinson and Wielaeart, 2012) and work examining biographical approaches and life story work in dementia care (McKeown et al., 2006; Moos and Björn, 2006; Williams and Keady, 2008). Intervention is focussed not only on the individual with semantic dementia but also on those around them within conversation and the everyday context in which life is lived.

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) provides a bio-psycho-social framework to conceptualise interventions for all health conditions. This framework has been extensively applied to stroke related aphasia (Simmons-Mackie and Kagan, 2007) although it is not widely used in dementia care, despite offering a meaningful way to conceptualise interventions (Bryan and Orange, 2005). Certain interventions aim to impact on body structures and functions; for dementia, this may be to change brain structures through medication or brain functions through cognitive rehabilitation. The framework also identifies psychosocial interventions that focus on restriction in taking part in everyday activities, such as conversation, and participation in life situations, including home and community life. A variety of factors influence activities and participation including barriers and facilitators in the environment such as physical, social, attitudinal and personal factors. As Figure 3.1 reveals, I have used this model replacing the generic ‘disorder/disease’ with ‘semantic dementia’ and specifying the area of ‘body function and structure’ affected as ‘brain functions and structures’, thus outlining the model for semantic dementia.

Currently, there are no medications available to treat the underlying condition in semantic dementia. Moreover, as I have illustrated in Chapter 1, communication research to date has largely focussed on improving brain functions, such as word finding. Experimental word relearning tasks have been adapted from aphasia therapy, with intervention aimed at the individual with semantic dementia (Carthey-Goulart et al., 2013; Jokel et al., 2014). This represents the blue box in Figure 3.1. In the aphasia literature, and in clinical speech and language therapy practice, such
approaches are often referred to as ‘impairment based approaches’ because the aim is to target the underlying impairment, or difficulty, in language function (Nickels and Croot, 2014).

Figure 3.1 - WHO ICF (2001) applied to semantic dementia

In contrast, Kindell et al. (2015) examined the practice of experienced speech and language therapists working with people with semantic dementia in older people’s mental health services in the North of England and noted interventions were aimed at supporting activities and facilitating participation, the yellow boxes in Figure 3.1. This included educating others to support the person with semantic dementia and provision of appropriate communication supports in the environment. Therapists focussed on important relationships for communication and the underpinning values used in practice were drawn from models of person centred and relationship centred care (Brooker, 2007; Nolan et al., 2004), rather than aphasia therapy. This thesis explores interventions that are in keeping with the practice discussed by Kindell et al. (2015) targeting the activity of conversation and, in turn, supporting participation in home and family life, through the provision of appropriate psychosocial support in the environment (World Health Organization, 2001).

3.3 Study Aims

The aims of the study are:

1. To explore everyday interaction in the home using a combination of conversation analysis of video data and biographical interviewing.
2. To use the information derived from these strands to design an individually tailored intervention which focusses on everyday conversation issues for each person with semantic dementia and their family carer(s), which includes interaction-focused therapy and life story work.

3. To explore and evaluate the effectiveness of this intervention.

4. To make recommendations for clinical practice.

The original overarching design to achieve these aims was through a case series design (Smith, 2012). In this approach, a consistent method for intervention was planned with each couple and fixed pre- and post-therapy outcome measures around conversation were planned. However, it became clear in the early stages of this project that the method for both assessment and therapy required further exploratory work with this population. Moreover, this initial design was too rigid to allow for a full exploration of each couples’ individual situation, including: their particular conversation challenges and needs, whether this approach was appropriate for their situation and a truly bespoke approach to therapy design. For example, as I will present in the case study data, the first two couples recruited presented with competing needs with respect to support and intervention, each requiring a different approach. Therefore, a case study design (Yin, 2009) was chosen to replace the case series design (Smith, 2012) as this allowed the freedom for a detailed exploration of each couples’ experiences in a real world setting, using multiple sources of evidence and intervention(s) co-constructed from the participant’s needs, value-system and biographical situation (Yin, 2009).

3.4 Researcher Reflexivity

An important and ongoing issue for me throughout this project was my role as a ‘practitioner-researcher’, i.e. a speech and language therapist doing research into areas of my own practice (Reed and Proctor, 1995). Clearly, this had both advantages and challenges at all stages of the research process and whilst space prevents me from discussing this at length, there are some particular issues worth noting. This research project involved exploration of interventions in a real world setting and, as such, I drew on my practitioner experience as well as the research methods in many of the decisions I made. My choice to move from a case series
study exploring the effectiveness of a fixed intervention to a case study design with a flexible and exploratory approach was heavily influenced by my clinical experience. The researcher in me understood the need to follow the original research protocol while the practitioner in me followed the needs of the participants.

An important aim for this project, and for the funder, was to make recommendations for clinical practice. As I have outlined, I had worked with people with semantic dementia for a number of years and I was aware of the challenges in living with this condition, including changes in conversational behaviour. There are particular issues with respect to methods to note here. Guendouzi and Müller (2006) argue that there are tensions for clinical researchers in using conversation analysis in its purest form in dementia, because this does not allow the analyst to use any pre-assumptions about their participants to guide analysis, including that derived from experience in clinical practice. They go on to say that clinical researchers will also be guided by the practical usefulness of their findings and ask the blunt question ‘What’s the use of this?’ (Guendouzi and Müller, 2006, p.10) to remind the researcher of the responsibility they have to contribute to clinically meaningful outcomes. Given the difficulty of this, and that this experience might illuminate the analysis, for example, in terms of what might be clinically significant, Guendouzi and Müller (2006) describe their approach as ‘adapted conversation analysis.’ They, however, warn researchers of the need to understand and stand back from their preconceived ideas and approach the data with an open mind with broad and exploratory questions in the first instance. This issue has obvious echoes of the debate regarding bracketing and reflexivity in qualitative research in general (Ahern, 1999; Cutcliffe, 2003).

Whilst I was adapting conversation analysis to encompass my clinical knowledge, I also, therefore, had to be careful about looking for what I might already expect to find in the data. I had noticed this issue in other work. For example, during my reading of the work of the Social Relations in Frontotemporal Dementia Group, I had been struck by the clinical language of some of the ethnographers, who were drawn from the department of anthropology. Reading through Mikesell (2009b), there are many instances of ethnographic field notes using clinically orientated terms about participants, e.g. ‘he seems really apathetic’ (p.84), ‘most of his oddness was in his lack of initiation towards me’ (p.100), ‘the trajectory of that [behaviour] really felt
impulse driven’ (p.101). As a result, I did question how much the clinical description of frontotemporal dementia influenced what the ethnographers were drawn towards in their observations and subsequent conversation analysis. Indeed, data analysis was sometimes explicitly driven by diagnostic criteria, e.g. ‘one aim is to explore the nature of a patient’s inappropriate behaviours in interaction, focusing on perseverative behaviours . . . which is one of the diagnostic criteria for frontotemporal dementia’ (Mikesell, 2010a, p.87). Here, I felt there was a danger of inadvertently focussing on particular cognitive deficits arising from the diagnostic criteria and something I needed to guard against.

My experience as a practitioner was also relevant to the narrative work; for example, this sensitising experience served as a resource for facilitating participant’s stories and this is appropriate in thematic narrative analysis (Riessman, 2008). This experience also enabled me to develop rapport with my participants, an important aspect of rigour in qualitative research (Davies and Dodd, 2002). Again though, I had to be aware not to make assumptions or focus down on certain storylines too quickly.

Reed and Procter (1995) discuss the particular challenges for practitioner-researchers and acknowledge the tensions between roles and the need to reconcile these as far as possible, rather than attempt to ignore or bury such issues. There were a number of these tensions during this project. As I was delivering an intervention, other members of the health and social care team often regarded me as a team member, rather than as a researcher, and I had to be careful to consider my role. For example, I was invited to clinical case conferences and I had to decline such offers stating my role was a research role. There were also instances when my experience as a practitioner came to the fore, for example, recognising and ensuring appropriate treatment for depression, highlighting issues of risk to clinical teams and facilitating access to appropriate support services.

3.5 Study Design

Contact with each of the recruited case studies was delivered over three phases, with all sessions delivered in the home of the person with semantic dementia. Contact was
undertaken over a longitudinal period, ranging from seven to 18 months. Figure 3.2 provides a summary of these phases, including the methods and approaches used within each phase. This is followed by a discussion and rationale for each of these three phases.

Figure 3.2 - Summary of phases and methods used in each case study
3.6 Phase One: Establishing a Baseline - Assessment

A period of assessment and information gathering was carried out in order to design an individually tailored therapy package. Four main sources of information were planned to assess needs in phase one of each case study and in the next sections I describe each of these methods in detail:

1. Conversation analysis.
2. Narrative analysis.
4. Quantitative measures.

3.6.1 Conversation Analysis

Talk can be analysed from various viewpoints using different methodologies, each with differing philosophical and theoretical underpinnings (Hamilton, 2005; Traynor, 2006). Conversation analysis is a naturalistic observation-based, qualitative research method described as ‘a systematic procedure for the analysis of recorded, naturally occurring talk produced in everyday human interaction’ (Beeke et al., 2007, p.137). Conversation analysis, with its emphasis on naturalistic data, appeared to provide the methodological tools to explore a range of issues in everyday conversation in semantic dementia in a non-judgemental manner. Conversation analysis is underpinned by a clear theoretical model, described as the ‘cumulative science of conversation’ (Silverman, 1998, p.41). The potential for this method has been demonstrated within behavioural variant frontotemporal dementia (Mikesell, 2010b; Mikesell, 2014; Smith, 2010).

Crucial to conversation analysis is the notion that talk is not just the exchange of information by two ‘speaker-hearers,’ but that individuals engaged in conversation orientate towards each other and mutually collaborate in order to produce a meaningful conversation (Hutchy and Wooffitt, 2008). In addition, conversation is not just the sum of the contributions of those involved, as each contribution takes account of, and is based upon, the previous contribution or turn (Perkins et al., 1998). Conversation analysis, therefore, analyses the part that both parties play in order to jointly negotiate the meaning within a given communicative context (Schegloff, 2003) and, therefore, offers a method to explore the natural
communicative behaviours of both the person with dementia and their family carer(s).

The purpose of conversation analysis is ‘to take singular sequences of conversation and tear them apart in such a way as to find rules, techniques, procedures, methods, maxims that can be used to generate the orderly features we find in the conversations we examine’ (Sacks, 1992, p.339). Conversation analysis is a method that allows not just the exploration of conversation, but aims to uncover recurring practices and behaviours evident within such conversations (Sidnell, 2010). In common with other qualitative methods, conversation analysis begins with the data and is not constrained by a pre-existing theory; accordingly, anything within the data is potentially of interest (Hutchy and Woofitt, 2008). This is particularly important for an area where little is known, such as semantic dementia. In addition, in contrast to many quantitative approaches used to study semantic dementia, the focus is not necessarily on communication breakdown but, equally, focusses on communicative success and potential patterns in the data may uncover either, or both, of these perspectives (Perkins et al., 1998).

Conversations evolve within a context of prior and upcoming turns which enables participants to both understand and design utterances within these turns. Thus turns at talk are part of larger sequences and making sense of this not only studies language in context but views language as context with each contribution providing a context in the sequence for the next contribution (Wilkinson, 1999). Decontextualising talk can be problematic for those with semantic dementia as the lack of sequential context potentially renders talk more ‘empty’ than it may appear within its natural context (Kindell, 2011). So, for example, an answer might be better understood placed within the original context of both the question posed and the answer given. Conversation analysis focusses on specific areas important to conversation including turn-taking, repair and topic management and has generated a body of literature examining these in normal conversation (Sidnell, 2010). Turn-taking has been shown to involve split second timing ordered by conventions that govern the participants’ coordination of turns to take the conversational floor (Sacks et al., 1974). Repair relates to practices that deal with potential ‘trouble sources’ that arise in the conversation such as problems of speaking, hearing or understanding
In terms of normal conversation, four patterns of repair sequence have been described depending on who initiates or highlights that a repair is needed, i.e. self- or other-initiated, and then who completes the repair. There is a preference for repair to be initiated and completed by the speaker with ‘other-initiated other-repair’ the least preferred and relatively rare in peer conversations, because of the corrective nature of such sequences (Schegloff et al., 1977). Topic management refers to the ability to initiate, effectively introduce and maintain appropriate topics of conversation (Sidnell, 2010).

Whilst conversation analysis is a specialist methodology that requires training, aspects of the underlying theory were familiar to me as a speech and language therapist and adaptations of the method have been used in clinical practice with relatively small amounts of additional training (Beeke et al., 2013b). I also considered this as a more transparent method for reporting than other methods in linguistics, for example systemic functional linguistics, which presents with a degree of linguistic complexity that may be difficult for those outside the field to understand. Given that this study is attempting to design an intervention for clinical practice, then conversation analysis seemed to be the most appropriate choice.

Conversation analysis has also been used successfully to drive interaction-focussed therapies in a number of fields, including aphasia post stroke (Lock et al., 2001; Simmons-Mackie et al., 2014; Wilkinson et al., 2011). Therapy using conversation analysis can deliver individually targeted intervention that takes account of individual need in real life settings, current helpful and unhelpful conversational strategies, and examines outcomes for both parties (Perkins et al., 1998; Wilkinson, 2010). This is in contrast to current communication intervention approaches in the semantic dementia literature which often target only the person with semantic dementia (Taylor et al., 2009).

In addition, as noted above, the starting point in conversation analysis is not with regard to deficit but with an open focus on the whole context, including all involved and all possibilities. Both skills and difficulties are examined and therapy becomes a jointly distributed property of the person with dementia and their family (Perkins et al., 1998). There has been increasing interest in dementia care into interventions that
involve both the person with dementia and their family carers in contrast to many earlier interventions that were targeted solely at the carer. Such combined intervention programmes may be of benefit to both parties (Brodaty and Donkin, 2009). A recent systematic review examining psychological interventions with carers found evidence supported those interventions which aim to increase knowledge of dementia and address communication (Elvish et al., 2012).

In summary, conversation analysis, with its focus on the study of naturally occurring talk, as well as its emphasis on the joint endeavour that is conversation, meets a number of objectives for this study. Conversation analysis can be used to record and analyse conversations. Interaction-focussed therapy builds on this assessment to work collaboratively with the person with semantic dementia and their family carers, to identify successful strategies for communication. In addition, because so little is known about conversation in semantic dementia, an in-depth qualitative method such as conversation analysis can provide the exploratory detail needed.

3.6.2 Practical Aspects in Recording and Transcribing Conversation

As suggested by Hydén (2013), this study used video recording of conversation (as well as audio data) as this allowed for analysis of embodied behaviour and not just speech. I, therefore, used a small camcorder placed on a tripod in the home to record conversation. Couples were asked to film themselves, without the researcher present, and three couples agreed to do this. They were asked to collect 20 minutes of conversation, either as a continuous conversation or in smaller chunks if this was easier, and were asked to talk about any topic they wished. The tripod was set up in a safe and suitable location identified by the couple as likely to capture everyday talk, e.g. at the kitchen table or sitting on the sofa. Participants were given practice time and advice on using the camcorder. At the next visit I discussed how recording had proceeded and gave any necessary advice on camera use. This process was repeated twice more aiming for 60 minutes of conversation. For the two couples reluctant to use the camera themselves, case studies four and five, audio recordings of life story interviews were used to analyse conversation skills initially and the video camera was taken along later at a mutually convenient session to record conversation with the couple, with me present. Where possible, I also video recorded
participants engaging in life story work and using the life story resources we had made together. Following this process, the videos were viewed on a number of occasions and sections of videotape were chosen for in-depth transcription. Particular sections were chosen where:

- Participants appeared natural in their interactions and sections were excluded where participants appeared self-conscious or particularly aware of the presence of the camera.
- A range of conversational issues were displayed.
- Issues raised by the person with semantic dementia or the family carer during interviews were displayed, therefore triangulating the data.

Transcription of data used an agreed system of transcription for conversation analysis (Jefferson, 2005, see Appendix 1). This method provides a greater level of detail than in many other transcription methods and pays particular attention to areas that may be deliberately omitted in other types of transcription, for example, hesitations are transcribed, pauses are timed, volume changes and overlaps in talk are coded. Where necessary, transcription of nonverbal behaviours, such as eye gaze and gesture also took place. Repeated viewings of data were required therefore to achieve this level of detail (Beeke et al., 2007).

I will now describe narrative analysis, the second method used to assess needs in phase one of each case study and outline why this was added to the research methods to build a picture of the mixed methods in this study.

### 3.6.3 Narrative Analysis

Narrative analysis relates to a family of methods used to study and interpret texts that have the storied form in common (Riessman, 2008). Williams and Keady (2008) advise that at its simplest level ‘narrative research and analysis is about asking for people’s stories, listening and making sense of them and establishing how individual stories are part of a wider ‘storied’ narrative of people’s lives’ (p.331). In narrative research approaches this information can be used to make sense of the interrelationship between identity, self and the social world (Williams and Keady, 2008), seeking to understand ‘the changing experiences and outlooks of individuals
in their daily lives’ (Roberts, 2002, p.1). Narrative inquiry ‘is grounded in the study of the particular’ (Radley and Chamberlain, 2001, p.331) and, therefore, enables exploration of in-depth experiences within case study research (Yin, 2009). This is important in a therapy study such as this where the aim is to focus on individual experiences within the context of couple and family relationships and tailor intervention to this individual need. Charon (2008) writing about the importance of narrative in medicine writes ‘narrative knowledge provides one person with a rich, resonant grasp of another’s situation as it unfolds in time’ (p.9) and this detail was important in planning intervention for this study. Atkinson (2002) outlines three stages in the process of interviewing individuals about their life story:

1. Preparing for the interview and understanding how a life story can be beneficial.
2. The process of the interview: guiding the person through the telling of his or her life story.
3. Transcribing and interpreting the material.

Narrative analysis began in the assessment phase and continued into the intervention as part of the life story work. Due to constraints of space in this thesis, in each case study a narrative summary is provided with further details outlined with respect to the life story work. I now turn to the issue of understanding why narrative analysis was beneficial for this project and used alongside the conversation analysis data.

3.6.4 Why Use Narrative Analysis with Conversation Analysis?
There were four related reasons why I chose to add narrative analysis with conversation analysis and I will now discuss each of these in turn.

1. To provide an understanding of the lived experience of each couple to support the conversation analysis
When conversation analysis has been mixed with other approaches, ethnography is most often the methodology of choice, as evident in the work of the Social Relations in Frontotemporal Dementia Group (Mates et al., 2010; Mikesell, 2010b; Smith, 2010; Torrisi, 2010). The rationale for this is generally to enhance the conversation analysis, particularly in less familiar settings where a more in-depth understanding of
various activities may be needed. Torrisi (2010) justifies the use of ethnography combined with conversation analysis, saying ‘through immersion in patients’ daily activities and observing them in a variety of contexts one develops a more accurate sense of which behaviours and traits are characteristic or salient’ (p.27). Heath (2011) argues for various reasons to engage in field work in video-based research including: ‘understanding the complex tasks in which people engage and the organisational constraints that bear upon the production of those tasks’ (p.262). Lastly, I have highlighted in the literature review that there is also evidence that couples may have different ways of ‘working’ or being a couple in the face of dementia (Hellström et al., 2007; Keady and Nolan, 2003; La Fontaine and Oyebode, 2014) and this may potentially impact on interaction. For these reasons, and in discussion with my supervisors, I felt an understanding of the lives of each couple would help me to understand why certain conversation features evident in the data might be significant in their lives. Therefore, I chose to use an additional method alongside conversation analysis to systematically explore this understanding. There were potentially various methods to achieve this from a qualitative stance, including ethnography, however, as I will outline narrative analysis, with a methodological emphasis on understanding life story information (Riessman, 2008; Sandelowski, 1991), had a great deal to offer this study.

2. To ensure that psychosocial factors were appropriately considered in therapy

As I have discussed in Chapter 2, there appear to be different challenges in describing conversation practices to those aiming to change conversation practices through therapy and whether the latter, in particular, requires engaging with psychological states and speaker intentions. For this reason, in aphasia therapy psychosocial aspects are often addressed alongside, or within, interaction-focused therapy (Lock et al., 2001). In keeping with a bio-psycho-social approach, a narrative approach was used to understand the broader psychosocial aspect of living with this condition for the person with semantic dementia and their spouse. A range of authors have shown that the creative application of narrative methods can enable people with dementia to tell their own story and this delivers unique insight into living with dementia (Angus and Bowen, 2011; Keady et al., 2007; Surr, 2006a). Narrative themes can also be explored within a relationship or family context (Aleman and
Helfrich, 2010; Daniels et al., 2007; Davies, 2011; Roach et al., 2014b; Williams and Keady, 2012). Understanding psychosocial issues for the person with dementia and their family embeds communication therapy into a context that takes account of relationship issues, past and present, and the broader day-to-day issues of living with semantic dementia.

3. To explore how personally related interests might influence interaction

It was important to deliver an in-depth exploration of topic choice within the conversations of people with semantic dementia. As I have illustrated, the literature notes that people with semantic dementia have a tendency to have particular personally related topics that they like to talk about and I had noticed this in my clinical practice. For example, Kertesz et al. (2010), rather disparagingly, refers to the talk of those with semantic dementia as ‘empty, garrulous speech with thematic perseverations’ (p.483). I was also aware of the proposal that personally relevant vocabulary was potentially maintained longer in semantic dementia (Julien et al., 2010; Snowden, 2015a; Snowden et al., 1994). I therefore needed a flexible way to capture and explore issues of personal relevance and topic choice within conversation; for example, why the topics an individual with semantic dementia choses to talk about may be important in their lives. In addition, knowledge of an individual’s life story provides the necessary context to interpret what may initially appear to be ‘empty speech’ (Mills, 2006; 1998). Given that such areas are highly unique to each individual and their life story, only narrative analysis delivered a method adequate for this task.

4. To enable life story work

Lastly, drawing on my clinical knowledge, it is common for people with semantic dementia and their family carers to report that unstructured conversation is increasingly difficult as the condition progresses and, therefore, that conversation during activities or particular structured tasks is more successful. Activities that might encourage conversation include doing everyday tasks together, engaging in shared hobbies and life story approaches. I had used life story work with people with semantic dementia in my clinical practice, and use of this approach was also noted by Kindell et al. (2015) in a representative group of speech and language therapists working in semantic dementia. I therefore considered that using life story work
would be particularly useful for those where unstructured conversation was difficult or frustrating.

### 3.6.5 Practical Aspects to Narrative Analysis

As I have discussed in Chapter 2, a number of authors have highlighted the interactive nature of storytelling in dementia and how the responses of others can facilitate such stories as well as the importance of this in supporting issues of identity and well-being (Hydén, 2011; Hydén and Orulv, 2009; Ramanathan, 1995). It was, therefore, crucial to consider how the person with semantic dementia could be supported to tell stories about their life, from the past and the present. The initial aim was to carry out audiotaped qualitative semi-structured narrative interviews with the person with dementia and the family carer, each conducted separately, and followed by at least one interview together. A degree of flexibility was planned and this was required, as three of the participants with semantic dementia needed or requested their spouse to be present during interviewing to support their communication.

It was expected that individuals might find telling the story of their life, as in a whole life story interview process (Atkinson, 2002), difficult due to their language and cognitive problems. This was, therefore, broken down into particular life events, including changes in life since the onset of semantic dementia. An outline of potential questions to be used in a semi-structured format was developed to prompt participants and this is included in Appendix 3. However, the intention was to follow the lead of the participants where possible and the stories they wanted to tell about their life, rather than impose a structure or series of questions upon them. Where necessary, interviews used objects, pictures or photographs from around the house to support the individual with semantic dementia to tell their story. It was expected that the methods required would vary between participants and a degree of creativity would be required. In practice, some participants were able to tell stories about their lives with little help, whilst for others support was required and, in some instances, spouses were able to provide details that the person with semantic dementia was unable to recall or convey. In reality, interviews began as part of the assessment period and continued into the life story intervention.
Field notes were recorded after each visit in order to gather further observations and impressions about life story and conversation and included in this were my clinical reflections about each visit and each case. This process was useful, therefore, to gather life story information, but also to observe how the person with semantic dementia was able to tell their story and what support they needed in order to do this. In line with research governance practices, audio recordings were transcribed by a professional transcribing service under contract by The University of Manchester.

3.6.6 Neuropsychological Assessments
To ensure diagnostic accuracy, a small battery of neuropsychological assessments was included to explore the underlying pattern of cognition. As well as allowing for comparison of performance across testing and natural conversation, the aim of using this data was to aid dissemination of results; for example, explanation of case studies to those who understand semantic dementia in terms of its neuropsychological impact or linking reported data to other case studies in the literature. The Addenbrookes’ Cognitive Evaluation-III (ACE-III) (Hsieh et al., 2013) was used to provide screening for a variety of cognitive domains including attention, memory, language and visuospatial skills. In addition, selected items from the ‘Cambridge 64 Battery’ were used to explore spoken and written comprehension of words and pictures, semantic associations and naming (Adlam et al., 2010). All participants were scored according to the requirements of the test and compared to control data. Participants in the first four case studies showed a pattern of cognitive difficulty consistent with semantic dementia, whilst the participant in case study five showed evidence of very mild semantic changes. Due to constraints of space in the main body of the thesis, all neuropsychological data are reported in Appendix 4.

3.6.7 Quantitative Measures
The following measures were also used:

1. The structured and semi-structured carer interviews from the Conversation Assessment Profile for People with Cognitive Impairment (CAPPCI, Perkins et al., 1997) and an adapted, simplified, version of this completed with the person with semantic dementia, where possible.
2. DEMQOL – Dementia Quality of Life Measure (Smith et al., 2005) or the carer proxy version of this tool.

3. The Care-giving Burden Scale (Gerritsen and van der Ende, 1994).

The CAPPCI interview outlines areas of concern with respect to communication and the carer rates them in terms of frequency and problem severity (Perkins et al., 1997). DEMQOL was included in order to explore potential changes in health related quality of life; this is a well-designed tool aiming to work across dementia subtypes and stages of dementia that focuses on issues beyond cognition (Banerjee et al., 2006; Smith et al., 2005). The tool can be completed by the person with dementia or a proxy version of the tool completed by a carer to describe the person’s quality of life. The Care-giving Burden Scale (Gerritsen and van der Ende, 1994) was included to examine changes in levels of carer stress and burden. The scale was chosen because a number of the questions relate to interaction and/or relationship issues and it is easy to understand and quick to administer. In addition, the scale has been described as well designed, with good construct validity (Oyebode, 2003).

The original intention for these measures was to use them as part of evaluating therapy within the case series design, thus using them as part of a pre- and post-therapy evaluation. The move to a case study design led to a more flexible and individualised approach to therapy and outcomes, as a result, were also unique. Therefore, whilst these tools were used in case study one to evaluate intervention, in subsequent case studies they were used only for assessment to gain a broader understanding of the case, rather than repeated to measure therapy outcomes.

3.7 Phase Two: The Intervention

There were two strands planned to intervention in phase two: interaction-focussed therapy and life story work. I will now explain each of these methods in turn. When I present each case study in Chapter 4, I will outline how each method was tailored to each case in practice.

3.7.1 Interaction-Focussed Therapy

This was based on previous interaction-focused intervention studies for aphasia arising from stroke, including studies occurring at the University of Manchester (see
for example, Fox, 2014). In these approaches video data are used in both assessment and intervention. Naturally occurring conversations are video recorded at home with people with aphasia talking to their family. This is then analysed using conversation analysis to allow for an understanding of the skills and difficulties evident with conversation for the person with aphasia in a naturalistic setting, but crucially also examined are the practices of others in facilitating, or not, the interactional skills of the person with aphasia. Therapy then follows a three-stage process outlined by Lock et al. (2001):

1. Raising the participants’ awareness of conversational features in general through hand-outs and discussion.
2. Raising participants’ awareness of their own conversational features by presenting clips to the couple from their own video tapes with in-depth discussion of behaviours present and potentially helpful and unhelpful strategies.
3. Providing methods of change for participants and problem solving as appropriate.

Modelling and role play of alternative strategies are used within sessions and between sessions trialling of alternative strategies takes place alongside other homework to reflect and embed change. Therapy is generally delivered over a six to eight sessions. This method was followed for couple one, but as I will illustrate, the focus for the project for the resulting case studies became the second strand to intervention: life story work and how the impact of this, particularly on interaction, can be explored.

### 3.7.2 Life Story Work

Life story work encompasses a range of biographical approaches used in health and social care. For the purposes of this study I am using the definition provided by McKeown et al. (2006) emphasising that life story work is an intervention ‘undertaken to elicit an account of some aspect of a person’s life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment, and aims to have an impact on the care the person receives’ (p.238). Whilst life story work can have multiple aims and impacts, the focus for this project was to explore
the ways life story work could contribute to supporting interaction at home. So, for example, exploring how a life story product might support participation in conversation. Such resources in clinical practice have most commonly been life story books although memory boxes, story boards, collages and films are all potentially possible (Kindell et al., 2014a; McKeown et al., 2013).

As part of this project, a review of life story templates available to engage people with dementia and their family carers in life story work was carried out (Kindell et al., 2014a). One of the problematic issues identified was the focus on predefined questions surrounding chronological milestones and details, e.g. birth, schooling, work etc. Thus, the process may be directed by the questions on the template elicited by the worker, rather than placing those issues of most interest to the person concerned central to the process. Given the problems with long term memory and understanding in semantic dementia, outlined in Chapter 1, I considered that this approach may be particularly unhelpful in semantic dementia. The person may, for example, no longer have any understanding of certain episodes in their life, may not comprehend some of the questions asked or recognise aspects of their own photographs. Therefore, I chose to use an approach that was led more by the person with semantic dementia and their concerns. This is outlined as follows:

1. Through narrative interviews and observation with the person with semantic dementia and their family carer, identify the topics and areas of the person’s life that appear to be relevant currently for interaction.
2. Explore ways to support these topics and abilities, e.g. through photographs, music and particular interaction practices.
3. Pilot initial materials, e.g. life story book, music DVD, with the individual and video or audio these sessions to collect their own words and reactions.
4. Use the person’s own words to provide personally relevant captions for these materials in the case of life story books and, again, pilot and refine. Examine the person’s responses and feedback from family carers in terms of other resource formats and refine as appropriate.
5. Repeat phases one to four as necessary.
6. Complete the resource.
In this way the aim of life story work for this project was very much about facilitating the participation of the person with semantic dementia in interaction, therefore, sharing much in common with alternative and augmentative communication aids (Fried-Oken et al., 2012).

3.8 Phase Three: Exploration of Outcomes
The tailored nature of therapy meant that outcomes had to be explored at an individual level for each couple. This included using conversation analysis of participants engaged in conversation or whilst using the life story resource, interviews and observations in the home situation recorded in field notes. I will outline the issues relevant to this process within the next section where I discuss managing the data.

3.9 Managing and Analysing the Data
One of the most challenging aspects of this study has been to manage the amount and variety of data gathered. Yin (2009) notes that using multiple sources of evidence is the first principle of data collection when engaged in case study designs. This study had evidence from the following sources:

- Video data and associated transcripts.
- Audio recordings of biographical interviews and life story work and associated transcripts.
- Semi-structured interviews (e.g. CAPPCI) and associated transcripts.
- Field notes containing observations and clinical reflections.
- Neuropsychological test results.
- Quantitative assessments.
- A reflective journal.

Managing this through creating a case study data base is the second principle advised by Yin (2009). I used case files to keep records for each case together, both in computer and hand held form. Neuropsychological test results and quantitative questionnaires were completed on paper and filed in case notes. Transcripts and field notes were entered into NVivo 10 to facilitate analysis. Four types of analysis occurred:
1. Within case analysis of conversation using conversation analysis.
2. Cross-case analysis of conversation data.
3. Cross-case thematic narrative analysis.
4. Triangulation of data across cases.

3.9.1 Within Case Analysis of Conversation
Transcripts of conversation data were analysed via NVivo 10 for recurring and striking conversation features using initial broad descriptive codes. Videos and audio data were used alongside transcripts to ensure data was viewed accurately. Conversation practices from these collections were then examined further outside of NVivo using conversation analysis. This study followed the approach described by Hutchby and Wooffitt (2008) to study recurring patterns and practices in the data. Steps are described as:
1. Highlight and then make a collection of examples of a particular practice within the data.
2. Analyse and describe one particular occurrence in detail.
3. Return to the data to see if other instances of the practice can be analysed and described in this way (Hutchby and Wooffitt, 2008).

In addition, extracts of video from each couple were viewed jointly during supervision and discussed to further explore and refine this analysis. As far as I am aware, using NVivo as the first part of the process is not a common practice in research using conversation analysis. However, given the amount and mix of data sources, I found this an efficient practice to manage the large data set. In addition, having all the evidence in one place helped me maintain Yin’s (2009) third principle in collecting case study research: maintain a chain of evidence. This principle is to allow clear cross referencing of evidence within the case study and into the case study report. Whilst I kept descriptive conversation codes separate from thematic narrative codes, I could compare across codes to explore recurring themes and linkages in the different strands of data. This cross referencing of different data sources helped me efficiently triangulate the data sources at a more in-depth level for both individual and cross-case analysis. This method was used to explore each couples’ conversation at home and was also used, where possible, to analyse
interaction using the life story resource we developed in the intervention. As will be shown as I outline each case study, part of this thesis became how to analyse ‘in-the-moment’ aspects of interaction in life story approaches using conversation analysis.

3.9.2 Cross-Case Analysis of Conversation Data
Conversation practices across case studies were compared and examined to uncover recurring practices and issues with interaction. These conversation issues were charted in table format. This method is that advised by Yin (2009) to display the data from the individual cases ‘according to some uniform framework’ (p.156) as is advised in cross-case synthesis in case study work.

3.9.3 Cross-Case Thematic Narrative Analysis
Transcripts of interviews and field notes were read and analysed on a case by case basis initially. As each case analysis was completed, work began on the next case. This process began by repeated reading of the transcripts, listening to the recorded interviews and viewing any visual data presented as part of the process, such as the viewing of photographs, video data, paintings etc. that illustrate the participant’s life story (Keady et al., 2009). Analysis was further guided by the approach suggested by Reissman (2008) where narratives were broken down into stories to create a sense of the whole. Transcripts were explored line by line and given a code that referred to a particular sequence within the text. Sequences chosen referred to a significant story, incident, or issue. Sections of interviews were also read separately by supervisors and codes were compared and discussed in supervision sessions. Once analysis of all cases had been completed codes were then compared and grouped in a hierarchical manner (Charmaz, 2006) to uncover recurring themes within the data. As before, coding and emergent themes were discussed and explored in supervision.

3.9.3 Triangulation of Data across Cases
Following the narrative analysis the table described in section 3.9.2, was expanded to encompass aspects of the narrative data and the intervention delivered in each case. This process allowed for triangulation of the various strands, and issues, as is advised in cross-case analysis of mixed methods data (Yin, 2009).
3.10 Rigour

I have considered issues of rigour by consulting a number of sources relating to both conversation analysis (Parry and Land, 2013; Peräkylä, 2011; Sidnell and Stivers, 2013; Silverman, 2006) and narrative analysis (Creswell, 2007; Creswell, 2012; Riessman, 2008), as well as referring to important texts and debates in the field of qualitative work generally (Davies and Dodd, 2002; Lincoln and Guba, 1985; Morse et al., 2002; Seale and Silverman, 1997). Difficulty in easily defining this area for this thesis arises, in part, from the lack of a standard method in narrative inquiry (Reissman, 2008) and lack of consideration of issues of rigour generally in the conversation analysis literature; for example, standard texts in the method often make few explicit references to such issues (e.g. Hutchby and Woofitt, 2008; Sidnell, 2010; Ten Have, 2007). In this thesis I have used the following principles:

- **Explicitly aiming for recurring practices in the conversation data** - It was clear during the literature review that some authors presented only one conversation extract and failed to take account of potential criticism that this might be ‘cherry picking’ the data. I, therefore, aimed to avoid this by video and audio recording significant amounts of talk for each couple, explicitly aiming for recurring patterns during analysis and using interview data to triangulate analysis, e.g. reports from family carers of significant features in talk.

- **Viewing turns and sequences not isolated lines of talk** - I took note of Silverman’s (2006) ‘common errors to avoid when doing conversation analysis,’ e.g. ‘trying to make sense of a single line of transcript or utterance in isolation from the surrounding talk’ (p.222) by explicitly examining talk in-situ as part of sequences of turns, but also as larger sequences, tracking back across the conversation, for example, to examine when ideas or topics were first introduced. This also relates to a key aspect of conversation analysis, validation through the next turn (Peräkylä, 2011), also referred to as the ‘proof procedure’, whereby ‘the next turn will show whether the interactants themselves treat the utterance in ways that are in accordance with the analysts interpretation’ (p.368). Analysis, therefore, concentrates on the participants within the encounter and how they behave and respond towards
one another in-the-moment, rather than use assumptions after the event from the analyst (Wilkinson, 1999).

- **Regarding transcripts as working documents not as perfect records of conversation data** - I used the transcription system as devised by Jefferson (2005) and received on-going advice in the method through supervision. Importantly, however, I was aware of the advice provided by Silverman (2006) that no transcript is ever perfect and the level of detail will depend on the research problem. Therefore, when examining conversation features I would regularly watch or listen to the original recording whilst engaging in analysis, for example, playing the original recording via my laptop, while engaging in further analysis of the transcript via my desktop computer. This emphasised that the data was the original recording of conversation and avoided mistakenly assuming issues from the transcript.

- **Using supervision to further explore and discuss data** - Regular supervision sessions allowed us to view video data together to compare and refine observations. These data sessions are an intrinsic aspect to adding rigour in conversation analysis. Likewise, to strengthen the narrative analysis, my primary supervisor also read through sections of interview transcript and in supervision we compared observations and discussed ideas. We also all met together as a supervision team to explore triangulation of data strands.

- **Audit trail** - I kept field notes of each encounter, typing these up as soon as possible after my visit, usually within 24 hours. These included a practical log of what I did at each visit as well as observations and my own clinical reflections of each case. Outside of this I kept a reflective journal outlining personal thoughts, issues and decisions with respect to the general research process. I also kept a log of all email conversations with supervisors about methods as these consisted of on-line systems of supervision and reflection. These systems aim to strengthen issues of persuasiveness (Riessman, 2008).

- **Prolonged contact** - I was involved with each couple for between seven and 18 months and this, along with the collection of different kinds of evidence, meant that I developed a deep understanding of their lives and this contributed to the credibility of my findings (Lincoln and Guba, 1985). Where possible, I also consulted with couples when engaging in analysis.
including: showing videotapes and discussing features that were evident; providing written summaries of research findings and asking for feedback; and discussing potential questions of analysis over the telephone after formal contact had ended. The design of the project, including the intervention nature of the study, also meant that analysis was on-going rather than being left until all data was collected. In this way I could discuss ideas and issues with participants as they emerged or use learning from one case to inform the next.

- **Audio recording and video recording and use of NVivo** - all interviews were audio recorded and transcribed in full, sections of video recordings were transcribed using a recognised system of conversation analysis transcription (Jefferson, 2005). All data was entered into NVivo 10 to ensure thorough and systematic analysis (Seale and Silverman, 1997).

### 3.11 Strengths and Limitations

This is an area I will return to within my discussion chapter. However, a point I have already raised is that the mixed methods approach presented as both a strength and a limitation. The arguments I have outlined above illustrate how the methods can be used in a complimentary manner with each potentially informing the other. However, both conversation analysis and narrative analysis are time consuming methods and there is a danger that inadequate time is given to either method. The study worked with a variety of data and the presentation of this, in terms of both adequate detail and constraints of space, was a challenge. Supervision was used to reflect on decisions within the research process and the format of this thesis.

### 3.12 Ethical Approval

Ethical approval for this study was given via the Integrated Research Approval System from South Manchester NHS Research Ethics Committee on 16th May 2012, a committee designated to consider studies involving individuals who may not have the capacity to consent for themselves, as is the case in this study. The study received research governance approval from three local mental health trusts and an acute trust that delivered a specialist neurology dementia clinic (see Appendix 5 for IRAS and research governance approval). The study was adopted onto the National
Institute for Health Research Clinical Network for Dementias and Neurodegeneration portfolio and advertised on their website as well as the website of the Frontotemporal Dementia Support Group.

The study presented with a significant number of ethical issues and these are outlined in Appendix 6, in the format presented to the ethics committee. One issue, for example, was the use of video data. The criteria excluded those people with semantic dementia where ‘the local speech and language therapist or psychiatry/neurology team had concerns regarding conflict or abuse within the household’ in order to reduce the possibility of recording inappropriate or potentially abusive interactions. If such interactions did arise it was intended that these were to be dealt with using local structures for protection of vulnerable adults. Involving individuals who lacked capacity was also a challenge and strict attention was paid to ways to assess and facilitate this in accordance with the Mental Capacity Act (British Psychological Society, 2008; Mental Capacity Act, 2005). A pictorial information sheet was used and during sessions this was cut up into individual sections and used in a similar format to ‘Talking Mats’ (Murphy and Oliver, 2013) to help facilitate consent. For those unable to consent for themselves a personal consultee was sought, with spouses acting as personal consultees in case studies two and three. Examples of information and consent sheets are contained in Appendices 7 and 8.

3.13 Sample Size and Issues of Recruitment

The following inclusion and exclusion criteria were used. Individuals were recruited who:

1. Had a confirmed diagnosis of semantic dementia from a specialist centre, using agreed criteria (Neary et al., 1998).
2. Were under the care of a neurology or psychiatry team or their local speech and language therapist.
3. Lived with, or had regular contact with, at least one primary carer.
4. Could consent for themselves and, if not, had a family member/primary carer who was willing to act as a personal consultee and able to agree their participation (Mental Capacity Act, 2005).
5. Had a primary carer and other family member(s), if appropriate, who were able to give their own consent.

6. The person with semantic dementia and/or the family carer were concerned about communication and wanted further advice and information on this area.

7. The person with semantic dementia was able to engage in simple everyday conversation.

Individuals were excluded where:

1. A formal diagnosis of semantic dementia had not been given or the person with semantic dementia and/or their family had yet to be informed of the diagnosis.

2. The diagnosis of semantic dementia had not been made using the Neary et al., (1998) criteria and/or a non-specialist (e.g. general practitioner, hospital consultant) had made the diagnosis without referral to a specialist.

3. The person with semantic dementia was residing on a hospital ward or in a long term care environment.

4. The local speech and language therapist or psychiatry/neurology team had concerns regarding conflict or abuse within the household.

5. The person with semantic dementia or the family carer was physically unwell.

6. Participants were unable to speak or understand English.

7. Participants had a current severe behavioural disorder and were unable to sit for even short periods of time.

The criteria were written in this way to ensure a firm diagnosis from a recognised specialist had been given and that the person was living at home with a family carer willing to take part alongside them. The stage of semantic dementia was left open to some degree because it was also unclear at the start of the study as to the type of issues or stage of condition that would be most appropriate for this kind of intervention. Behaviours that challenged were not a reason for exclusion, but severe behavioural difficulties were identified as a reason for exclusion because of the difficulty in facilitating an adequate assessment and the need for more extensive support than this study could offer.
Recruitment was expected to be challenging for a variety of reasons including the relative rarity of semantic dementia and variation in rates of diagnosis and understanding of the condition. In some areas there was a lack of an agreed referral and management pathway for younger people with dementia, including those with rarer dementias, and so individuals with semantic dementia could potentially present to a range of services including mental health services, memory clinics, neurology services, speech and language therapists and other disciplines depending on the initial presentation of their condition.

The recruitment process is outlined in Appendix 9. I delivered presentations about the research to a number of teams and groups across Greater Manchester and the North West between July 2012 and January 2013. The purpose of this was to raise awareness of the study, as well as explain the inclusion/exclusion criteria to ensure that health and social care professionals were able to consider appropriate individuals. Staff members were then asked to approach potential individuals and draw their attention to the study. As expected, recruitment was challenging for the reasons outlined above. In addition, some services reported that they did not provide an ongoing community support service for this client group because this was delivered through the tertiary neurology service, despite the tertiary service reporting this was not their role. Lastly, both clinicians and service users, at times, reported that the use of video as a means of data collection was an issue for them.

In the final event five couples were recruited to the study. The recruitment strategy also identified another seven couples who did not take part. This included two couples who, in line with study criteria were not appropriate, one due to staff concerns over high levels of conflict in the household, the other because extensive therapy had already delivered many of the intervention tasks. Five couples declined to take part, either to myself or colleagues: three couples expressed concern over the video procedure, another couple declined because the spouse felt the person with semantic dementia might be upset by the research and a final couple declined for unknown reasons. The final number included in this study reflects the in-depth qualitative analysis involved in both conversation analysis (Wilkinson, 2010) and biographical interviewing (Roberts, 2002; Keady et al., 2009) and the individually tailored nature of the intervention programme, including the time taken to make and pilot the life
story products. At the same time this number allows for both the individual profiles of each couple to be explored, as well as group commonalities, along with learning from each case applied to the next in a flexible and iterative manner (Yin, 2009).

3.14 Summary

An overview of the methodologies and methods used in this study has been presented in this chapter. The study presented with practical and ethical challenges in ensuring approval via the Integrated Research Approval System and research governance agreement with each trust. Recruitment of this rarer dementia was difficult but five couples took part in the study. On a practical level delivering each aspect of the research design, including various pre- and post-therapy assessments and delivering interventions alongside took a considerable amount of time. Between sessions there was also work in developing life story resources. The mixed methods approach was innovative but also had challenges. Theoretically, the lack of previous research in the field to guide research practice, including the fact that the two methods in the project had not been used together in either research or clinical practice, meant that a step by step method was not available. Research and clinical decisions had to be considered carefully, drawing on research knowledge, clinical knowledge and exploring issues in supervision. The organic nature of the study meant interventions were tailored to each couple and the circumstances for this are described within each case study, leading to a variety of potential outcomes. I will now present the five couples who took part in this study in turn, presenting them in the order in which they were recruited. All names are pseudonyms and other contextual details have been altered in order to maintain confidentiality.
CHAPTER 4

Presentation of Case Studies

4.1 Introduction
The five case studies are described in this chapter, presented in the order in which participants were recruited; the research, analysis and presentation representing the iterative process that took place. In all five cases the person and their spouse took part in the research project and in case study two, Sarah and Reg’s daughter gave her consent to also take part. Each couple was visited between eight and 20 times at home with a total of 74 home visits conducted over the duration of the study. In reporting each case, the same main and sub-headings are used to demonstrate the consistency across the data and to allow for cross-case analysis that is presented in Chapter 5. Where necessary, Appendices are referred to for additional case study information. Interventions were tailored to each situation with couple one, Peter and Joanna, taking part in interaction-focussed therapy and all couples taking part in life story work. The case studies represent the trajectory of semantic dementia, from its early onset through to more advanced presentation and, in one case study, through to the death of the person living with semantic dementia. The chapter commences with an overview of the data set and direction of each tailored intervention.

4.2 Data Set Overview

Case study one [C1]: Peter and Joanna – The focus of this case study was the use of interaction-focussed therapy to change patterns of interaction in the home situation and co-production of a portable life story resource.

Case study two [C2]: Sarah and Reg – A life story music DVD was co-produced to enhance verbal, embodied and emotional connections at home.

Case study three [C3]: Doug and Karina – A summary sheet ‘Making Connections’ was made with Karina, describing ways to make connections with Doug to help the staff in his new care home understand and facilitate his interaction.

Case study four [C4]: Ruby and Brian – Topic based life story books were made to help focus the conversation.
Case study five [C5]: Ken and Brenda – ‘Enriched self-generated life story work’ was carried out by Ken, a man living with semantic dementia.

Table 4.1 provides a summary of the case study data contained in this thesis.

Table 4.1 - Summary of case study data

<table>
<thead>
<tr>
<th>Case study</th>
<th>Visits 2-3 hrs</th>
<th>Interviews recorded</th>
<th>Video data</th>
<th>Neuro-psychol</th>
<th>Other measures</th>
<th>Life story format/issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>20</td>
<td>7</td>
<td>3:30 hrs. – as couple 0:47 hrs. – couple + researcher</td>
<td>Yes</td>
<td>CAPPCI DEMQOL Care-giving Burden Scale</td>
<td>Portable pocket book + books for home</td>
</tr>
<tr>
<td></td>
<td>(5:52 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C2</td>
<td>20</td>
<td>10</td>
<td>3:00 hrs. – as couple 0:55 hrs. – couple + researcher</td>
<td>Yes</td>
<td>CAPPCI DEMQOL Care-giving Burden Scale</td>
<td>Music DVD</td>
</tr>
<tr>
<td></td>
<td>(11:07 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td>8</td>
<td>8</td>
<td>00:09 hrs. – as couple 1:32 hrs. – couple + researcher</td>
<td>No</td>
<td>CAPPCI Care-giving Burden Scale</td>
<td>‘Making Connections’ sheet for care home</td>
</tr>
<tr>
<td></td>
<td>(8:23 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C4</td>
<td>15</td>
<td>9</td>
<td>0:57 hrs. – couple + researcher</td>
<td>Yes</td>
<td>CAPPCI DEMQOL Care-giving Burden Scale</td>
<td>2 books</td>
</tr>
<tr>
<td></td>
<td>(14:08 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C5</td>
<td>11</td>
<td>4</td>
<td>1:07 hrs. – couple + researcher</td>
<td>Yes</td>
<td>CAPPCI DEMQOL Care-giving Burden Scale</td>
<td>Self-generated work on computer</td>
</tr>
<tr>
<td></td>
<td>(5:41 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALL</td>
<td>74</td>
<td>38</td>
<td>11:57 hrs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(45:11 hrs.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.3 Case Study One - Peter and Joanna

4.3.1 Introduction
I will now outline the first case study. This case, of the five presented, was the most similar to that envisaged within the initial case series design of this study, in terms of the structure of the interaction-focussed therapy. This case study presented with complex challenges, arising from the need for support for the participants, from this project and more broadly from health and social care. It was a brave move for Peter and Joanna to take part in a project of this nature, given the stress they were experiencing and I respect and thank them for their honesty in describing their circumstances.

4.3.2 Background
Peter (67 years old) and Joanna (64 years old) had been married for 43 years. They had two daughters and four grandchildren, who all lived some distance away. Peter was a retired accountant. He had received his diagnosis of semantic dementia from a specialist memory clinic five years previously and the speech and language therapist from this clinic referred him into the study. They were reviewed by the clinic once a year. A nurse from the specialist memory clinic visited Joanna at home to offer a carer support service once a month, with no other local services involved. When I met them Peter was still driving, going out alone and regularly played tennis.

4.3.3 Our Initial Encounters
It was clear from the moment I met Peter and Joanna on the 24th August 2012 that they were struggling to manage the impact of semantic dementia on their lives. Joanna freely admitted that life as a carer was hard; she missed their old life and Peter’s communication problems were stressful. In contrast, Peter remarked that he could have died young like their neighbour and this seemed to be his way of coming to terms with the diagnosis (i.e. life could have been worse) and remaining positive, although it was clear from Joanna’s reaction to Peter’s story that she did not share this view. I wrote in my notes at the time you can feel the tension at times between them (F 2/10/12), indicating their different points of view in coping with the dementia. In conversation, Peter displayed significant word finding difficulties and
frustration. However, he did not appear confused and sat listening intently with good eye contact and facial expression. He tried to show me things, for example, on my first visit he opened the door with his tennis score card in his hand, ready to show me. Peter showed me a small diary with a notes page containing the word ‘jog’ written repeatedly, each word recorded after a daily run and a larger daily journal in which he wrote each day’s events, with evidence of mistakes crossed out. Joanna was concerned that Peter showed these possessions to visitors; in particular, she did not want others to see the change in Peter’s skills and so react to him differently.

4.3.4 Establishing a Baseline - Assessment

I made 20 visits to the house over a 16 month period as summarised in Table 4.2. Assessments took place over five visits from November to December 2012.

Semi-structured and Structured Interviews

Interviews about their life together now and in the past began in the assessment phase and continued as part of the life story work. Due to Peter’s severe word finding problems, it was difficult to interview him without Joanna present as he often called her to help. As a result, most of the interviews were carried out with them both together or Joanna on her own. There were, however, shorter opportunities to talk to Peter alone; for example, when I initially arrived and Joanna offered to make tea or finished off household chores. These encounters were recorded within field notes.

Joanna explained how strong they had been as a couple prior to the semantic dementia and her strong feelings of loss for their old life together, including a loss of conversation and of the practical and emotional connections they had shared in the past (I 26/11/12). Peter, in contrast, often spoke about what he could still do, e.g. he was still able to play tennis and go for a run (F 24/8/12). During these interviews, and repeated during our time together, Joanna shared that she felt she was not very good at caring and reflecting back over the good times made her more sad to think about all that had been ‘lost’ (I 07/11/12).

Joanna’s overall score using the Care-giving Burden Scale (Gerritsen & van der Ende, 1994) was 9/13 demonstrating the high level of burden she was experiencing
(I 26/11/12). Using the DEMQOL-Proxy (Smith et al., 2005) Joanna reported that Peter had a good quality of life overall, with relatively few worries other than forgetting the day and a mild degree of frustration arising out of his word finding problems, giving a score of 101/124. This score is above the mean of 92, reported for those with mild dementia in a study by Banerjee et al. (2006).

Table 4.2 - Summary of visits with Peter and Joanna

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>24/08/12</td>
<td>Initial meeting to explain research</td>
</tr>
<tr>
<td>2</td>
<td>02/10/12</td>
<td>Facilitate consent and set up video camera</td>
</tr>
<tr>
<td>3</td>
<td>07/11/12</td>
<td>Neuropsychology and interviews, review camera</td>
</tr>
<tr>
<td>4</td>
<td>13/11/12</td>
<td>Interviews, review camera</td>
</tr>
<tr>
<td>5</td>
<td>26/11/12</td>
<td>Interviews, review camera</td>
</tr>
<tr>
<td>6</td>
<td>18/12/12</td>
<td>Discussion around assessment and future therapy</td>
</tr>
<tr>
<td>7</td>
<td>07/01/13</td>
<td>Discussion – what is semantic dementia?</td>
</tr>
<tr>
<td>8</td>
<td>14/01/13</td>
<td>Issues of wellbeing and distress in conversation, video used</td>
</tr>
<tr>
<td>9</td>
<td>18/02/13</td>
<td>Managing understanding &amp; word finding, video used</td>
</tr>
<tr>
<td>10</td>
<td>08/03/13</td>
<td>Discussion – prioritising conversation flow over accuracy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Introduction to life story work</td>
</tr>
<tr>
<td>11</td>
<td>26/03/13</td>
<td>Developing life story resource, photographs to support talk</td>
</tr>
<tr>
<td>12</td>
<td>16/04/13</td>
<td>Discussion - test questions and frustration, Recorded stories</td>
</tr>
<tr>
<td>13</td>
<td>17/05/13</td>
<td>Introduction of portable life story resource</td>
</tr>
<tr>
<td>14</td>
<td>12/06/13</td>
<td>Continue to gather materials and Peter’s words for captions</td>
</tr>
<tr>
<td>15</td>
<td>24/06/13</td>
<td>Discussion - managing repetitive questions, video used</td>
</tr>
<tr>
<td>16</td>
<td>17/07/13</td>
<td>Practice using life story books and portable book</td>
</tr>
<tr>
<td>17</td>
<td>12/08/13</td>
<td>Discussion - managing behaviour</td>
</tr>
<tr>
<td>18</td>
<td>25/10/13</td>
<td>Reassessment - interviews and camera at home</td>
</tr>
<tr>
<td>19</td>
<td>15/11/13</td>
<td>Reassessment - interviews and camera at home</td>
</tr>
<tr>
<td>20</td>
<td>09/12/13</td>
<td>Final visit and plans for future support</td>
</tr>
</tbody>
</table>

**Interviews about Conversation and Analysis of Video Data**

The CAPPCI (Perkins, Whitworth & Lesser 1997) was used to explore reported changes in everyday conversation (I 13/11/12 and I 26/11/12 - see Appendix 10 for full scores). Joanna described problems in all areas of conversation with only articulation, prosody and fluctuations as unproblematic. She reported the following areas as occurring in ‘high frequency’ and as ‘a big problem’: a lack of conversation from Peter, his difficulties repairing his own talk when she prompted him, failure to understand, overuse of vague terms and difficulty drawing inferences.
After some initial worries that their lack of conversation would affect the video process, between visit two (02/10/12) and visit six (18/12/12), Peter and Joanna recorded 187 minutes of conversation, more than I had suggested. Appendix 10 contains a summary of pre- and post-therapy video data. Conversation analysis showed a number of areas of note and four of these areas are presented here.

**Issue 1 - The Pursuit of Accuracy - Management of Word Finding Difficulties, Repair and ‘Test Questions’**

There were numerous instances where Peter would struggle to find a word and become frustrated. He was often unable to repair this trouble without help. Joanna would allow Peter time to think and often attempted to give him clues to say the correct word, if she knew it. This led to long sections of conversation solely concerned with Peter’s attempts to find a target word, when in fact the word was often known to Joanna. There were instances in the data of Joanna correcting Peter. In addition, Joanna was observed to start up conversations with a question for Peter, the answer to which required a particular word, or piece of information, which she already knew. Such questions have been termed ‘test questions’ in the aphasia literature because the question posed has an answer that is already known to the enquirer (Simmons-Mackie et al., 2014). Due to his word finding difficulties Peter would often be unable to find the word to answer the question. Extract one is provided here to illustrate this, with another extract 2, given in Appendix 10.

**Extract 1) -Test question - the newspaper (V 10/11/12)**

Peter and Joanna are having breakfast and the conversation turns to what Peter is going to do that day. In this extract there are two test questions, highlighted in yellow, in lines 002 and 006, the responses to which Joanna already knows. Whilst Peter is able to say the day of the week, the focus quickly becomes the name of the newspaper.

```
001 P oh I’ve got to get the paper
002 J yeah what day is it today
003 P Saturday
004 J mm
005 P so I always get the paper
006 J yup (1.0) which paper do we have on a Saturday
007 P (3.0) not the Sunday ↑times (13.0) the erm
008 (6.0) the Saturday ↑times
```
Here, Joanna repeatedly attempts to encourage Peter to self-repair and say the correct word, e.g. in 009 “no the other one” (using an information cue); 012 “the ↑daily” (using a phrase completion cue); 018 “come on what is it” (giving further encouragement); in each instance, therefore, it is Joanna initiating the repair. In 007 Peter attempts to cue himself into the word and, whilst this appears to be a resourceful strategy, it is not successful: “not the Sunday ↑times (13.0) the erm (6.0) the Saturday ↑times.” In 013 he again perseverates on the wrong paper, “the Daily Mail”. As a result there are a number of instances of Joanna using “no”, shaking her head or using other utterances to inform Peter that he has not yet provided the target word, e.g. 009 “no the other one”; 014 “I don’t think so”; 017 “no”; 020 “no that’s tomorrow isn’t it”.

This is part of a larger sequence which lasts for two minutes and 54 seconds, until Joanne gives him the paper’s name (Daily Telegraph). In conversation analysis terms this is referred to as ‘other repair’, i.e. the repair is completed by Joanna. The result of this extended sequence is that Peter’s lack of competence in word retrieval is highlighted repeatedly and the topic of conversation halts to focus on the pursuit of one particular word to the exclusion of all else.

Across the pre-therapy data, of 187 minutes, there are 104 instances of Joanna using test questions and attempting to cue Peter to say a particular target word. There are six very long sequences lasting respectively in minutes: 8:59, 3:50, 2:54, 2:08, 1:57, 1:23. Again, this contrasts with normal conversation where short repair sequences
are preferred (Schegloff et al., 1977). Reducing ‘correcting’ behaviours (other-repair) and test questions in conversation partners have often been targets for conversation therapy in the aphasia literature (Simmons-Mackie et al., 2014) and together have been noted to be aspects of a teaching or ‘pedagogic’ style from conversation partners (Lock et al., 2001; Wilkinson et al., 2010b).

**Issue Two: Comprehension Difficulties**

Analysis of the video reveals instances of Peter’s difficulties in understanding but also that these were often subtle in nature within the conversation. Therefore, it would be a failure in an expected verbal or physical response that would demonstrate that Peter had not understood, such as not laughing when this was expected during a ‘funny story’ or a failure to follow instructions. Extract 3 below demonstrates this issue and another, extract 4, is provided in Appendix 10.

**Extract 3) - Comprehension - the toaster (V 11/11/12)**

Here Peter and Joanna are sitting at the table having breakfast:

001 P ((starts to clear dishes))
002 J just press the toaster down Peter will you
003 P ((reaching for and looking at the coffee pot))
004 P ((looks at the coffee pot, perplexed))
005 J the toaster ((points))
006 P oh ((gets up))

In line 002 Joanna asks Peter to “press the toaster down” whilst she is reaching for the coffee pot. Her verbal instruction and nonverbal behavior appear to be in conflict for Peter and he looks at the coffee pot, wondering what to do (004 in yellow). In 005 Joanna clarifies this with an additional consistent nonverbal cue (a point) and this is enough, this time, for Peter to understand and carry out the instruction in 006. In other instances in the data Joanna supports Peter’s comprehension by using visual materials and he responds well to this. For example, a conversation about food for Christmas is supported with a brochure of food items and talk about the weather is helped by the weather forecast on the iPad. Joanna also reported using ‘Google images’ on the iPad to show Peter pictures often helped.
Issue Three: Managing Reduced Repertoire of Topics and Repetitive Questions

One of the most difficult areas surrounded Peter’s repetitive conversational behaviours. There were at least two aspects to this:

   i) Reduced repertoire of topics of conversation.

   ii) Repetitive questions about their routine.

   i) Reduced Repertoire of Topics of Conversation

Peter demonstrated recurring themes and phrases in his talk leading to less spontaneity and flexibility in the conversation. It is interesting that in the data Joanna does not often encourage Peter to elaborate on these themes and this was also evident on my visits, as extract 5 illustrates. Here, after attending a group, Peter talks about telling someone there about playing the guitar:

Extract 5) - Favourite topic - guitar (V 30/11/12)

001 P yes and I said to him I’ve I got to level six
002 J yeah
003 P and I always did ((lips twitching)) and it’s
004 my memory problem but I always did no no I
005 almost got into level six yeah
006 J when you went last week to the club you told me the same thing you told me that you had said
007 exactly the same thing
008 P well I didn’t do it now
010 J then
011 P oh
012 J you just told me that’s what you said to him
013 P oh
014 J you just told me that’s what you said to him
015 P oh er yeah oh ok ok
016 J so I think you’ve been repeating yourself again
017 P no I haven’t I haven’t

It is a life-long regret for Peter that he did not pass his level six guitar examinations. Here, though, Joanna is observed to pursue the fact that Peter told her the same story last week (006-008 in yellow). For Peter this sounds like a complaint and in line 017 he begins to sound frustrated and the opportunity to recount his full story is lost.

   ii) Repetitive Questions about their Routine

The video showed that Peter repeatedly asked “what are we doing today” or related questions (see Appendix 10 for extract 6 as an example). Peter appeared to have little
awareness of this and initially Joanna would patiently explain, in detail, the day ahead. However, often just a few minutes later, this cycle would be repeated with Joanna again outlining the day but with, understandable, increasing frustration and at times pointing out that Peter was being repetitive. Within the pre-therapy data there are 37 instances where Joanna comments directly on Peter’s repetition or other direct comments that his talk was problematic (“I’ve already told you that”, “you’ve said that before”, “that doesn’t make any sense to me”).

Further analysis showed that Peter often asked about the day after a lapse in the conversation, suggesting at least one of the reasons for this was an attempt to initiate interaction. This was reinforced by analysis of Peter’s nonverbal behaviour, whereby he would repeatedly look at Joanna during silence in the conversation and then eventually use this question. Therefore, he may have retained the ability to know that something needed to be said, but his limited repertoire meant he had few conversational tools to do this more effectively and hence asked about the day. This illustrated the everyday tensions for them both; it was challenging for Joanna to remain patient, time and again, in response to such questions but pointing out the repetition to Peter was unlikely to lead to change. In addition, a detailed explanation of the routine each time appeared unnecessary and conversation or other form of distraction may have helped.

**Issue Four: Tension and Emotions in Conversation**

There were emotional consequences for both parties arising out of the conversation challenges. In the pre-therapy data there are 31 instances of metalinguistic comments from Peter to indicate his frustration or awareness that his performance fell short of that required within the interaction, e.g. “I know what I am saying”; “I’m hopeless”; “have I got it right?” He apologised for his failings in the conversation or would comment “it’s my memory problem.” These interactional challenges, therefore, continually reminded Peter about his difficulties and potentially this was damaging for his well-being and sense of self. In the videos Joanna looked exhausted trying to stimulate Peter to talk or find a particular word, despite trying her best, and likewise, this also seemed damaging to her sense of competence as a carer.
4.3.4 Formulating and Delivering the Intervention

These instances demonstrated how Peter and Joanna had gone from a strong couple with a shared life, to a life with a lack of connection, dominated by frustration and tensions. Joanna had commented at interview (I 7/11/12) and often made reference to the fact that she felt it was important to keep Peter active and stimulate his memory. This notion may therefore be behind the pedagogic behaviours and, given that such behaviours are rare in peer to peer conversation (Schegloff et al., 1977), this raises the possibility that this is an adaptation arising from her perceived role within the caregiving process. However, whilst this strategy of stimulating Peter’s memory and word finding may have worked in the earlier stages of Peter’s semantic dementia, this adaptation was no longer successful and new ways of managing this were needed that would cause less distress to both of them. Overall, I wanted to move away from the focus on the transactional components of conversation, e.g. getting the right information, to one that considered the broader interactional aspects, including the well-being of both parties in the interaction and so my goals for therapy were as follows:

Within interaction-focused therapy:
1. To reduce the current pedagogic style.
2. To explore management of repetitive questions and topics.
3. To emphasise ways to support understanding.
4. To reduce the tension in conversation for both parties, e.g. reduce frustration.

Within life story work:
5. To develop materials that could support interaction both now and in the future in a manner that would ‘scaffold’ Peter’s participation.
6. To provide an opportunity for Peter and Joanna to connect emotionally within interaction using shared memories and experiences.

The materials used within interaction-focused therapy would be drawn from the video data and interviews about everyday communication issues, therefore representing an ecologically valid way to explore their everyday interaction. Secondly, life story work would take place alongside to support conversation. Therapy was delivered over 11 sessions from January 2013 to July 2013, with an
interval of two to four weeks between sessions depending on Peter and Joanna’s availability. Sessions lasted two to three hours, rather than one and a half hours initially planned. A table outlining each session in more detail is provided in Appendix 10.

### 4.3.5 Interaction-Focussed Therapy

Discussions were based around viewing extracts of video, discussing written information or issues in interaction as they arose naturally in the session. Both Peter and Joanna were present for all sessions, except the session concerning repetitive behaviour (session 15) where only Joanna was present, because of the challenging nature of this topic. Therapy began in session seven with the provision of two sheets outlining: ‘What is Semantic Dementia’ and ‘Living with Semantic Dementia: Some Common Questions’. To write these I used information from a number of sources to gain inspiration including: The Frontotemporal Dementia Support Group, UK (2013), Cerebral Function Unit, Manchester, UK (2013), Alzheimer’s Society UK, (2013), University of South California, Memory and Ageing Centre (2013) and used instances of real life conversation issues gathered from their own video data. Ensuring the broader condition was understood was a key foundation for therapy. Copies of these are provided in Appendix 10. An early general theme in therapy was the need to make adaptations: practically, emotionally (recognising stress) and in conversation.

Videos were used in sessions to illustrate topics in a sensitive manner and the wellbeing of both parties was always explored, along with a non-judgemental exploration of issues and potential strategies. Joanna was very apprehensive about viewing the videos and so the first one shown illustrated a number of positive behaviours (session eight). In session nine we looked at videos where comprehension was a challenge and also instances where Joanna had supported Peter’s understanding well by using the iPad or nonverbal cues. During session 10, Joanna commented that giving Peter the word when he was struggling was “like giving up on him”, therefore giving in to the dementia and not fighting against it. We were able to explore this and to recognise that strategies that had been possible early in the dementia were no longer appropriate, because Peter was no longer able to
correct himself when prompted. I used two contrasting videos to reinforce this: one involving a long pursuit of one particular word and, another, where Joanna had given Peter words when he struggled, leading to more topics covered in the time available and therefore more, not less, stimulation for him. In this way therapy delicately challenged Joanna’s practice and belief about stimulating Peter to find words and explored another way for her to help Peter, and herself, within the interaction.

Further written sheets were provided as a summary for Joanna after discussion of each area had taken place using Peter and Joanna’s words and real life illustrations. The SPPARC (Lock et al., 2001) was also consulted for further information that might help them (copies of the set of sheets given to Peter and Joanna, appropriately anonymised, are provided in Appendix 10. Sheets were given at the next session or sent in password protected format to Joanna with a request for her to confirm this was an accurate description of our discussion. For example, in session 10, Joanna came up with the term ‘feeding him the line’ when discussing how she had begun to provide Peter with the words rather than expecting him to come up with them himself. This term was therefore used in the summary sheets from that session. This allowed for exploration of the area and consideration of what was/was not working with interaction, rather than a therapist driven approach. All sheets were also sent to Peter and Joanna’s daughters via email (in password protected formats) following Peter and Joanna’s request, so they could view the information.

By the end of therapy we had agreed a number of strategies to support communication:

1. Avoid test questions to elicit particular target words.
2. Give Peter the word if he is struggling and the word is obvious.
3. If the word is not obvious, try to guess.
4. Use a ‘give in gracefully phrase’ if frustration is rising, e.g. ‘don’t think about it now, I’m sure it will come back to you later’ and then distract.
5. Use visual and nonverbal prompts to help Peter’s understanding, e.g. showing him leaflets, pictures or the iPad and using hand and eye pointing.
6. Whilst repetitive questions are very frustrating, there is nothing to be gained in pointing out repetition. Consider:
a. Avoid continually reiterating information in detail; answer any questions briefly, e.g. “you are off to tennis today.”
b. Use distraction.
c. Use Peter’s diary to show him and written prompts in direct sight, e.g. on the breakfast table.

4.3.6 Life story work

Within the life story work, I aimed to concentrate on two aspects. Firstly, the aim was to use the approach as a vehicle to help Peter and Joanna connect emotionally during sessions using past memories and topics of conversation. The second aim was to produce an acceptable resource that could be used in everyday life in an on-going way to support Peter’s conversation.

The life story resources were generated with both Peter and Joanna in sessions 10 – 16 (March – July 2013). We began with those areas that Peter liked to talk about and expanded from that point over our sessions, gradually developing the resources. Given Peter’s love of tennis was clear from the moment I met him, it was easy to know where to begin. Peter proudly showed me a photo of a cup he had won and he was able to recognise photographs I had sourced from the internet of important tennis clubs. Peter was able to recognise people and places he was familiar with in photographs, showing no associative agnosia in these instances. This was a good way to spark off memories and use as a joint focus for conversation. I audio or video recorded Peter’s stories about these photographs and events. I used these recorded words to illustrate captions for the photographs, particularly paying attention to words he might be likely to search for but have difficulty finding. Where possible I chose words with regular spellings because of Peter’s surface dyslexia. I scanned each photo into power-point and then inserted a typed caption underneath. As the materials were coming together, Peter and Joanna also included their daughters in discussions about topics and photographs and their daughters as a result sent me some photographs and suggestions for items that I then discussed with Peter. We considered where, when and with whom Peter would use the life story materials and two formats were chosen:
1. A5 black presentation display books (to keep at home and use with Joanna and other visitors).

2. A small black pocket size business card holder (to keep in his pocket when out and show others as he wished).

Given Peter had been a businessman I considered these formats appropriate and I wanted them to look professional as I was aware Joanna was worried about Peter showing visitors his diaries because of the mistakes contained in them. We grouped the information within the home life story work into three A5 books with the titles:

- People important to me
- Places important to me
- Things I like to do

The books had a mixture of information from the past and the present. We took pictures of Peter engaging in current activities he often talked about, including jogging, playing the guitar and various household chores. Important topics were chosen for his pocket book and here I reduced pictures in size and only inserted essential captions. Peter had no spatial difficulties so he could easily negotiate this small format.

Some adjustments were needed when materials were piloted. I noticed that Peter was not always making use of the written word underneath, e.g. searching for a person’s name but not noticing that it was written underneath. I therefore began to insert names in small yellow boxes directly onto the photo next to the individual’s face (as well as the caption underneath) and this helped greatly. Materials were therefore continually added, piloted and refined in this way.

4.3.7 Outcomes of Intervention

Between October and December 2013 I carried out four visits to conduct post-therapy assessments. It was evident that Peter and Joanna had made a number of adaptations to their lives. Peter was attending social groups/day care four days per week and going out for a walk with a support worker at the weekend. He had stopped driving but was still jogging and playing some tennis.
Semi-Structured and Structured Interviews

The Care-giving Burden Scale (Gerritsen & van der Ende, 1994) with Joanna again indicated a high level of burden (score 10/13) at much the same level as before therapy. This was consistent with my clinical reflection, as I felt that Joanna had made some changes but she still found the situation challenging. Peter was still reported by Joanna to have a good quality of life using the DEMQOL-Proxy version (Smith et al., 2006) with a score of 106/124 (similar to the pre-therapy score of 101/124).

The CAPPCI (Perkins, Whitworth & Lesser 1997) was used again (see Appendix 10 for full scores) with Joanna reporting, as before, problems across all domains apart from articulation, prosody, and fluctuations. Those areas reported now as occurring ‘frequently’ and as ‘a big problem’ were: a lack of conversation from Peter, difficulty initiating new topics with repeated themes in conversation and presence of repeated questions and comments. Whilst a lack of conversation was reported before intervention the other areas described as additionally problematic may reflect Peter’s declining skills over the 10 months, including his decreasing repertoire of topics of conversation and his increase in repetitive questions about the routine, which was becoming increasingly important to him.

Those areas that were reported as occurring ‘frequently’ and as ‘a big problem’ before therapy (ability to repair own turn when initiated by conversational partner, failure in comprehension, overuse of pronouns or proforms, ability to make inferences) were still reported as occurring frequently but were now reported as being ‘a bit of a problem’. It was hard to ascertain if these results represent natural variability in Joanna’s perceptions of conversational issues or Joanna’s change in management of these areas after therapy. However, at interview Joanna reported a number of changes in the way she managed Peter’s communication difficulties (I 15/11/13), e.g. “I tend to let things go a lot now, but sometimes I just don’t get it at all and we just have to leave it” and “I don’t even try to correct him.” She also reported she had stopped trying to teach Peter things as this extract shows:

Again, I can’t teach him, I tried in the early days [describes Peter using ‘she’ instead of ‘Lesley’] And I would then say ‘who, who’ [he’d say] ‘she does’ and I would then say ‘who is she?’ [He’d say] ‘her’. But, again, I’ve
realised he’s not going to say ‘Lesley’ (I 15/11/13).

There also appeared to be a change in Joanna’s awareness of when to move away from a potential argument. For example, Peter often thought he had met famous people on the television and whilst before she might have corrected him, she reported: “now, I just say, okay, you know if he thinks he has, because he gets quite shirty if you say, you’ve not met him, how would you ever have encountered him?” (I 15/11/13).

Joanna seemed more aware of Peter’s comprehension difficulties, whether this was due to the decline in skill in this area or therapy it is not possible to say:

you’re lowering your expectations of comprehension all the time, I’m giving him less and less, or fewer and fewer instructions . . . you might as well go to the brush for the kitchen floor yourself and get it, and put it in his hand, than to say ‘just go and get the brush’, because he’ll come back with the ironing board or a bucket or something (I 15/11/13).

The area that remained highly problematic for Joanna was Peter’s repetitive questions, as she admitted honestly here; “I try to be patient and go along with what he’s talking about, but I do say to him sometimes, ‘Peter you’ve said this 16 times this afternoon’” (I 15/11/13).

Conversation Data

Videos and transcripts of all videos were analysed before and after therapy to explore if those areas that were targeted in therapy showed change. Codes were developed, in consultation with one of my supervisors. This involved making explicit the goals of therapy and setting initial codes to illustrate targeted behaviours followed by a process of examining the video together and further refining codes to ensure that communication behaviours could be adequately defined, noted and counted. Frustration, for both parties, was a particularly difficult area to analyse as it involved both verbal and nonverbal elements and demarcation of each instance was problematic. It was more helpful to limit this to Peter’s comments about his interactional performance, including comments that indicated frustration (“I know what I’m saying”) or awareness that his performance fell short (“I’m hopeless”).
Such methods have been used in other interaction-focussed therapy studies in aphasia (Fox, 2014; Wilkinson and Wielaeart, 2012) and there is some overlap with the method used by Ellis-Grey et al. (2014) to analyse person centred care at home in dementia.

For this process, it was important to consider examples in their situated context including verbal and nonverbal behaviours such as gestural cues, facial expression and tone and, using conversation analysis principles, to consider how the participants themselves treated utterances at the time. Codes that were used for this were:

1. **Known response elicitor (KRE):** Joanna asking questions when the answer was already known (test questions) or giving prompts/cues to facilitate a particular word/information.

2. **Orientating to error or repetition (OER):** Joanna making explicit verbal comments/other responses (see below) about Peter’s interactional performance indicating it is falling short of that required. This included:
   a. Direct comments about Peter’s repetition or that he was not making sense.
   b. Rejecting Peter’s response with overt indication that he had said something wrong.
   c. Correcting Peter’s talk.

3. **Orientating to own performance (OOP):** Verbal comments from Peter regarding his interactional performance that indicate awareness that his performance falls short of that required.

Codes are listed in the Appendix 10 with examples (see Table A10.4). As pre- and post-therapy data sets were unequal, rates per minute for each code were calculated. In the post-therapy data, a section of video was excluded from the analysis because Peter and Joanna were reading aloud from the newspaper and naming photographs from an album rather than engaging in conversation. Table 4.3 outlines full figures with Figure 4.1 illustrating results in a bar chart. This illustrates that following therapy there had been a reduction in all areas coded. Following statistical advice, I examined the 95% confidence intervals for these figures and this indicates that only ‘orientating to error or repetition’ showed statistically significant change (p ≤ 0.1), with a lack of overlap in the confidence interval (Norman and Streiner, 2008).
number of instances of ‘direct’ correction, within the category of ‘orientating to error or repetition’ was particularly notable, reducing from 44 instances pre-therapy (rate 0.24 per minute) to zero after therapy, i.e. in the data after therapy Joanna did not directly correct Peter any longer.

Table 4.3 - Codes and rates per minute of behaviours pre- and post-therapy

<table>
<thead>
<tr>
<th>Code</th>
<th>Pre 187 mins</th>
<th>Pre rate per minute</th>
<th>Post 35.5 mins</th>
<th>Post rate per minute</th>
</tr>
</thead>
<tbody>
<tr>
<td>KRE</td>
<td>104</td>
<td>0.56</td>
<td>14</td>
<td>0.39</td>
</tr>
<tr>
<td>OER</td>
<td>109</td>
<td>0.58</td>
<td>7</td>
<td>0.20</td>
</tr>
<tr>
<td>OOP</td>
<td>31</td>
<td>0.17</td>
<td>5</td>
<td>0.14</td>
</tr>
</tbody>
</table>

Confidence Interval

Confidence Interval

OOP 31 0.17 5 0.14

Confidence Interval

0.117 – 0.2287 0.0523 – 0.3029

The time it took to resolve test questions and pedagogic sequences was also reduced post-therapy. The pre-therapy data contain a number of these long sequences (in minutes, with the video code): 2:54 (V 10/11/12), 1:23 (V 12/11/12), 8:59 (V 16/11/12), 3:50 (V 16/11/12), 2:08 (V 19/11/12) and 1:57 (V 11/12/12). In the post-
therapy data, most of these instances were resolved quickly, with only two instances lasting over 20 seconds: 1:29 (V 18/08/13) and 0:46 (V 02/09/13).

The data demonstrate that whilst test questions were used, Peter could either successfully answer these and, if not, Joanna provided him with the answer or used other means to ‘end the test’ more quickly, e.g. moving onto a new topic, as the following extract illustrates. Here Joanna asks Peter if he knows where their daughter is away on holiday, the topic of an earlier conversation:

**Extract 7) – Giving the word – in Wales (V 18/08/13)**

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>J</td>
<td>Do you know where they ↑are</td>
<td></td>
</tr>
<tr>
<td>P</td>
<td>no</td>
<td></td>
</tr>
<tr>
<td>J</td>
<td>they’re in Wales aren’t they</td>
<td></td>
</tr>
<tr>
<td>P</td>
<td>yeah</td>
<td></td>
</tr>
</tbody>
</table>

Here, when Peter does not know the answer to the test question posed (001, in yellow), probably because he has forgotten, she quickly gives him the word with no attempts to cue him or comment that he has forgotten. Interestingly, the tag question at the end of the sentence draws Peter in to agree in line 004. Another example is provided in Appendix 10 (Extract 8).

**Life Story Resources**

Peter enjoyed the life story work very much. It was noticeable on my visits that the books were always readily available in the lounge and Peter enjoyed looking through the books whenever I visited as this field note entry illustrates: *We started looking through the life story stuff I had amassed. Peter was extremely interested in this and delighted with the material, as we went through it he said “wow” repeatedly, also “yeeesss”!* (F 17/05/15).

Following therapy I interviewed them both about the life story work (I 25/10/13). It quickly became apparent that this exercise seemed to have a dual purpose. Joanna was able to *describe* in detail how Peter used the books. Peter, in contrast, said he liked the books very much and then spent the rest of the interview turning the pages himself, showing me each page and telling me about the people and places, therefore
demonstrating their use. In this way, they each gave their view of the intervention, using the skills available to them, thus forming two strands of information:

- Reflections on the development and use of the books from Joanna.
- An in-the-moment demonstration of the books from Peter.

Joanna reported that Peter often looked through the books on his own, picking them up without prompting, saying: “he certainly enjoys it, he gets a lot of enjoyment out of looking at them” (I 25/10/13). Peter had spontaneously showed the books to people visiting the house, including their financial advisor, friends, daughters and grandchildren. Joanna was accepting of this, in marked contrast with how uncomfortable she was with Peter showing others his diary, noting: “I think they’ve been a tremendous tool, they’ve been really helpful”.

There was evidence of Peter using the books in other settings:

- The day care centres regularly asked for his book and reported that he spontaneously showed it to them.
- Peter was admitted for emergency respite in August 2013 and he took his books with him and Joanna reported that this had been helpful for the staff to get to know him.

There was also evidence of other family members using visual materials to support Peter’s conversation, for example:

- Joanna reported about a visit Peter made to their daughters: “she got out some of the photograph albums . . . which got Peter talking about (describes a number of things) . . . she thought the photographs were a great idea. She said it really prompted some conversation” (I 26/03/13).
- On visits to their other daughter they had taken to getting out old videos of the grandchildren as toddlers and Peter enjoyed this (I 25/10/13).
- For Peter’s birthday, his son-in-law sent a large framed picture of one of Peter’s favourite holiday destinations and Peter was delighted with this, often showing the picture to visitors (I 25/10/13).
The therapy, therefore, had influenced the behaviour of other family members, perhaps arising out of Peter and Joanna’s wish to include their daughters in the process, despite them not living locally.

Joanna felt it was important that the books reflected Peter’s current concerns, such as the staged photographs of Peter loading the dishwasher or going out for a jog, remarking:

*You perhaps wouldn’t incorporate [those] in a normal life story, because it’s so incidental and not important (J - Yeah, but at the moment, that is really important) Yes, they’re the things that resonate. . . I think that’s very important. I don’t know how Peter’s memory functions now compared to someone with Alzheimer’s, but I know people with Alzheimer’s often, sort of, regress back to their early life, Peter doesn’t seem to do that (I 25/10/13).*

Joanna went on to say that despite work being: “*such a big part of his life, too much of a part really*” that Peter never spoke about work, reporting: “*and that’s just gone, he doesn’t mention the company name or any of the people who work there*” (I 25/10/13). Clearly then, there were current activities that appeared to ‘resonate’ for Peter and some important past events that in contrast no longer held his interest.

Both the audio and video data showed Peter using the books with great enthusiasm. The written word often supported his conversation, for example, he read aloud words from the text that spontaneously he would often struggle to say and written words also supported me to help Peter, by reading from the text and elaborating the topic (see Appendix 10 for two examples, extracts 9 and 10). The books contained a wider range of topics than Peter used in spontaneous conversation, which tended to revolve around a small number of topics (as evidenced in the video and interview data). This provided some relief for Joanna from the narrow range of topics present in their current everyday lives.

In terms of the process of life story work, Peter was the focus of attention and the topic was about him and his life, in contrast to the usual format of our sessions which most often focussed on the problems they were dealing with currently. As an
observer I felt that during these tasks Peter and Joanna connected more than usual emotionally, talking about “the good old days” as Joanna often described it. Even our sitting positions were different during this activity. Usually, I would sit on the sofa and Peter and Joanna would each sit in their usual armchairs at opposite ends of the lounge. The life story book meant we all gathered on the sofa around Peter, with him controlling the book and turning the pages when he wanted, with us following his lead, as Figure 4.2, taken from a video recorded session shows (V 11/05/2013). The pictures have been altered in line with consent given from Peter and Joanna.

For Joanna she talked about reflecting on the past now, with a degree of mixed emotion:

> I spend a lot of time now thinking about the past . . . you know, there’s a lot of history in our marriage, isn’t there, and I find I’m recalling all sorts of times and experiences, both happy and sad times and how we dealt with them, more particularly, how Peter dealt with them I think (I 25/10/13).

Figure 4.2 - Looking through the life story book
From left to right: Joanna, Peter and Jackie
4.3.8 Reflections on the Intervention
As a practitioner-researcher this case study presented with a degree of complexity for me. Whilst the research intervention changed conversational behaviours and equipped Peter with life story resources to foster connections, life throughout remained challenging for Peter and Joanna. As a practitioner I was unable to ignore the overall lack of support within the wider care plan and just deliver the research intervention. As a result, alongside the therapy we spent time talking about increasing the care plan and accessing services and this is one of the reasons sessions were longer than initially planned. In my clinical judgement I believe that the therapy helped support Peter and Joanna whilst it was occurring and had many positive aspects, but would have been better if it had been available earlier in their post-diagnostic lives to help them cope and adapt to life with semantic dementia.

4.3.9 Closing Contact and Future Needs
Over the time I was involved with Peter and Joanna there was a rapid expansion in the care plan, but the situation remained challenging. Towards the end of our time together Peter and Joanna began to access increasing support from residential respite services. I completed the research with them in December 2013 and in March 2014 Peter was admitted into full time care. Joanna currently visits Peter regularly and tries to build her life without him.

4.4 Case Study 2 – Sarah and Reg

4.4.1 Introduction
Couple two, Sarah and Reg, presented very differently to the first case study. Although Sarah had been living with semantic dementia for a similar length of time, there were significant differences in the presentation of the condition, the level of support they received and in their on-going adaptation. As assessment of their conversation at home took place it became clear that, in many ways, they had positively adapted to life with semantic dementia. The focus of this case study, therefore, became an exploration of the utility of life story work, the opportunities and challenges it created and finally the production of a personalised music DVD with the family.
4.4.2 Background
Sarah and Reg (64 and 66 years old, respectively) were both retired and had lived within their current community for all their married life (43 years), first in their family house and now in a bungalow. They had one daughter, Harriet and two grandchildren, who lived locally. Sarah had been born with a physical disability that affected movement in her left arm and leg and walked with the aid of splints. Sarah had been diagnosed with semantic dementia four years before our first encounter and a community psychiatric nurse visited regularly. A care package provided a designated support worker to take Sarah out three afternoons a week and to ‘dementia clubs’ (their words) on another two afternoons.

4.4.3 Our Initial Encounters
Sarah and Reg were warm and welcoming and both seemed in good spirits on my first visit on the 6th December 2012. I noticed numerous red objects in the lounge: cushions, the chairs, a rug, vases etc. and it transpired that Sarah had experienced a phase of shopping for red items. Sarah sat in a certain chair so she could put her legs up. She talked about her physical disability and how her mum had encouraged her to get on with life, both at school and in her working life. Sarah’s speech was fluent and she did not struggle to find words. She did, however, keep asking Reg the same questions, most often asking if they were going out that day. Reg seemed relaxed and patiently answered Sarah’s questions each time or went to the kitchen to get Sarah a scone, a cup of tea, fresh chewing gum and so on, as she requested. Reg was keen to get involved in the research in any way that might be helpful.

4.4.4 Establishing a Baseline - Assessment
I was involved with Sarah and Reg over an 18 month period and made 21 visits in total to the house as summarised in Table 4.4. Assessments took place over five visits from January to April 2013; with a further six visits to explore potential life story approaches, from April through to July 2013.
Table 4.4 - Summary of visits with Sarah and Reg

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>06/12/12</td>
<td>Explain research</td>
</tr>
<tr>
<td>2</td>
<td>11/01/13</td>
<td>Facilitate consent, set up video camera at home</td>
</tr>
<tr>
<td>3</td>
<td>28/01/13</td>
<td>Interview and neuropsychology, review camera</td>
</tr>
<tr>
<td>4</td>
<td>26/02/13</td>
<td>Interview, review camera</td>
</tr>
<tr>
<td>5</td>
<td>21/03/13</td>
<td>Neuropsychology, CAPPCI interview</td>
</tr>
<tr>
<td>6</td>
<td>08/04/13</td>
<td>Interview, looking through life story book</td>
</tr>
<tr>
<td>7</td>
<td>23/04/13</td>
<td>Video with life story book &amp; singing songs together</td>
</tr>
<tr>
<td>8</td>
<td>20/05/13</td>
<td>Discussion around music and video shown of us singing</td>
</tr>
<tr>
<td>9</td>
<td>14/06/13</td>
<td>Video –a ‘feely’ box</td>
</tr>
<tr>
<td>10</td>
<td>05/07/13</td>
<td>Session looking through video data gathered so far</td>
</tr>
<tr>
<td>11</td>
<td>22/07/13</td>
<td>Life story template to explore memories</td>
</tr>
<tr>
<td>12</td>
<td>02/10/13</td>
<td>Exploring reaction to songs &amp; gathering other ideas</td>
</tr>
<tr>
<td>13</td>
<td>26/10/13</td>
<td>Weekend visit to discuss with Harriet</td>
</tr>
<tr>
<td>14</td>
<td>22/11/13</td>
<td>Recording the DVD with family</td>
</tr>
<tr>
<td>15</td>
<td>13/12/13</td>
<td>Draft DVD (laptop) shown to Sarah, Reg and Harriet</td>
</tr>
<tr>
<td>16</td>
<td>19/12/13</td>
<td>Draft DVD given to family, Sarah unwell</td>
</tr>
<tr>
<td>17</td>
<td>06/01/14</td>
<td>Draft DVD shown on TV to Sarah (session video recorded)</td>
</tr>
<tr>
<td>18</td>
<td>31/01/14</td>
<td>Visit to discuss DVD with Harriet</td>
</tr>
<tr>
<td>19</td>
<td>26/02/14</td>
<td>DVD Final format given to family, research process discussed</td>
</tr>
<tr>
<td>20</td>
<td>09/03/14</td>
<td>Visit to observe Sarah at day care</td>
</tr>
<tr>
<td>21</td>
<td>19/03/14</td>
<td>Final evaluation visit</td>
</tr>
<tr>
<td>22</td>
<td>29/08/14</td>
<td>Telephone call to review situation</td>
</tr>
</tbody>
</table>

**Semi-structured and Structured Interviews**

I usually interviewed Sarah and Reg together because they talked openly in front of one another, including about the dementia, although one interview was carried out with Reg on his own. The most significant aspect to these interviews was how well they had both adapted to living with semantic dementia. Whilst Reg said that he was frustrated with Sarah’s habits, for example, asking the same questions over again or having a fixed routine each day, he remembered it was not her fault. It was not the life they had planned, he said but: “you play the hand that you’ve been dealt in life, no matter how good or how bad it is” (I 26/02/13). Sarah would often make spontaneous references to “this dementia” whilst pointing to her head, indicating her awareness of her condition, but would also remark that she had to “get on with it”:

“this dementia thing, whatever it is, it’s done a lot to me. I’ve lost the car, haven’t I and everything now. So, it has done a lot, but I just have to try and get on with it, don’t I” (I 26/02/13). I was struck during these interviews by the remarkable lack of
bitterness that either of them expressed that, after a life time of a physical disability, Sarah now had dementia.

Reg was able to tell me about the various ways he managed Sarah’s symptoms and described his problem solving over the years. He often talked about the need to accept Sarah as she was and not argue, as shown in this interview:

*Well, I just accept whatever she says now, is how it will be for her, that’s her life now, that’s why I’ve got to accept her ways of looking at things, rather than me saying, oh no, that’s what you should be doing . . . If I wanted to be awkward and fight my corner every time to put a point over, we’d get nowhere, and I think life would be harder then . . . to be honest, I don’t see the point in arguing with somebody who can’t help what they’re doing.* (126/02/13).

Given Reg’s relaxed manner it was a surprise that the level of burden he reported on the Care-giving Burden Scale (Gerritsen and van der Ende 1994) was one of the highest in the study (score 10/13). Using the DEMQOL-Proxy (Smith et al., 2005) Reg reported that Sarah had a good quality of life overall although her score was 88/124. This was mainly because she had been distressed over the preceding week because of repeated migraines and this had affected her mood. Reg reported that Sarah did worry at times about her memory and the fact that she got muddled. However, she had few worries to do with her performance in everyday life.

**Interviews about Conversation and Analysis of Video Data**

Interviews using the CAPPCI (Perkins et al., 1997) and videos recorded by Sarah and Reg alone, and with myself, were analysed. Whilst Reg reported that Sarah had many difficulties with communication he felt that these difficulties were not particularly problematic for him: “*Nothing really bothers me, Jackie* [referring to the interviewer], *to be honest really. You could say that about all the questions. It doesn’t bother me, I just accept it*” (26/02/14). All scores for problem ratings on the CAPPCI were therefore zero (not a problem). The video data and my observations reinforced this view. The formal scores for the CAPPCI are reported in full in Appendix 11.
Sarah and Reg recorded 127 minutes and 49 seconds of video. This was watched on two occasions and detailed notes were made to gain an overall impression of their everyday conversation, with recurring features noted. Forty one minutes and 25 seconds was chosen for detailed transcription because these sections illustrated a range of issues present in the data. A table summarising the video data that was transcribed is provided in Appendix 11. Analysis using a conversation analysis approach showed a number of areas of note and five of these areas are presented here.

**Issue 1 - A Lack of Conversation and Minimal Acknowledgements**

Reg reported that Sarah did not initiate conversation and experienced difficulties maintaining the conversation, often using minimal acknowledgements (‘mm’, ‘oh’):

\[I \text{ don’t think she’s reluctant to talk. I don’t think she knows how to talk, to get into a conversation. It’s more of what can I say to add to the conversation? I mean even last night my daughter and one of my grand-kiddies was here and she sits and looks at them until they say something (I 21/03/13).}\]

This is evident in the video data; in the first half of the video recorded on 14/01/14, Reg can be seen, unsuccessfully, trying to encourage Sarah to talk using various questions and her responses are “yeah”, “I don’t know”, “mm”. The conversation appears one-sided, with Reg doing most of the work. There is also a lack of eye contact, facial expression and other embodied behaviours in the interaction. An extract of this conversation, extract 11, is provided in Appendix 11.

**Issue 2 - Reduced Repertoire of Topics of Conversation**

When asked if Sarah introduced new topics Reg replied with an emphatic “never” (I 26/02/13), saying she had favourite topics she liked to talk about. As I got to know them I learnt these topics and it became apparent, analysing the videos and spending time with the couple, that Reg knew the ‘triggers’ to involve Sarah in these topics and actively used them. During a later session, Reg talked about this:

\[I \text{ know the right button to press to make her say these things, if you’re with me, start talking to me . . . like you’ve just said about her mum telling her to go get this job, we could be sat here, if I just mention that,}\]
that will get the same response . . . because I know that that seems to be up there all the time. Everything else has gone (I 22/07/13).

Recurring topics are evident in the video data. In the video recorded on the 14/01/14 (discussed above), Sarah becomes talkative when the conversation turns to playing bingo at her friend’s house and how her friend’s son likes to win (a recurring topic in the data). In extract 12, Reg initiates the topic (in yellow); he knows how to encourage Sarah to talk (her use of direct reported speech, i.e. the dialogue, in bold):

**Extract 12) - Favourite topic - bingo (V 14/01/14)**

001 R ʂ what does he say when he [(2 syllables)]
002 S 뤄 oh he] loves it
003 R ʂ does he
004 S ʂ yeah I’ve won mum mum I’ve won [(animated facial expression + pitch/loudness)]
005 R ʂ he gets excited
006 S ʂ yeah
007 R ʂ oh it’s a shame for him n’t it
009 S ʂ yeah you should see him like that when he wins
010 R ʂ er it’s just so nice you know (2.0) he gets so excited and Jill says have you won again mum
012 ʂ I’ve won I’ve won and starts going on ((moves hands)) you know
014 R ʂ gets proper excited [(by it )]
015 S ʂ yeah 
016 R ʂ does he
017 S ʂ yeah mmm
018 R ʂ only a little game n’t it but he gets excited
019 R ʂ well it’s a shame for him n’t it
020 S ʂ it is a shame for him it is I mean she does
021 R ʂ her best she’s brilliant with him

In this extract in line 001 (in yellow) Reg use a test question: “what does he say when he (unintelligible)” Reg knows the answer to this, the purpose of this appears to be to facilitate Sarah’s participation with an easy topic. In contrast to the test questions in case study one, the test question here appears to facilitate participation of a particular topic. Sarah becomes more animated and proceeds to say and act out the story. In this extract, as in other examples of this same story in this data set, the words “it’s a shame” also recur and this appears tied in with the fact that the son is a man with learning disabilities. Over-all there is much more participation, both
verbally and nonverbally from Sarah in this conversation than the earlier part of the video described above (displayed in Appendix 11).

Across the data set there are particular recurring topics and Reg, on his part, can be seen not only to tolerate Sarah’s repeated stories, but in some instances actively encourage them. Again, in a later interview (I 22/07/13), I ask Reg if he felt this helped keep Sarah connected to her own identity and he agreed saying “it’s true, because I think if I don’t give her those, what has she got? Because she won’t come up with something herself”.

**Issue 3 - Direct Reported Speech and Other Acting Behaviours**

Within Sarah’s favourite topics there were recurring sequences of her acting out what she or other individuals had said, in the form of direct reported speech (i.e. directly acting out their dialogue), along with appropriate changes in pitch and loudness, facial expression and use of gesture. In extract 12, just presented, Sarah was seen to act out what her friend’s son would say when he won the bingo game: “I’ve won mum, mum I’ve won” ((animated facial expression + pitch/loudness)) (004-005) and then her friend, Jill’s, response: “have you won again” (011). This behaviour of direct reported speech and acting out occur in many of Sarah’s stories (another extract, extract 13 is presented in Appendix 11). Direct reported speech in enactment sequences have been reported in a study examining conversation in semantic dementia (Kindell et al., 2013).

**Issue 4 - Living with Repetitive Questions**

When asked if Sarah would ask the same questions or make the same remarks over again Reg reported: “very, very, very frequently” (I 26/02/13). Sarah had some awareness of this behaviour and spontaneously commented on this while they were alone together in the video data: “I’m sorry for driving you mad . . . I just repeat myself and go on and on” (V 12/02/13). Whilst Reg reported that he found Sarah’s repetitive questions very wearing, there were no overt complaints from him that she was repeating herself either in the video data or during visits. Sarah is observed to ask the same questions, often about the routine, to which Reg would then patiently answer. For example, the video recorded on 18/01/13 is six minutes and 44 seconds long and Sarah can be seen to ask when the support worker is coming on six
occasions (this extract, Extract 14, is contained in Appendix 11). Reg does admit he is not always this patient, for example, finding things more stressful when he is tired or at night when Sarah keeps getting up and his patience becomes frayed.

**Issue 5 - Facilitating Participation with Tag Questions**

Reg made no mention of this strategy during interviews; however, the video shows numerous instances of Reg using tag questions at the end of his sentences. It is likely that this is an unconscious strategy or adaptation to her difficulties. Two examples of this are presented below:

**Extract 15) - Tag question 1 bingo (V 13/02/13)**

001 R And you’re goin playin the game with
002 S James are ya
003 S Yeah

**Extract 16) - Tag question 2 sleep (V 09/02/013)**

001 R So you didn’t have a good night’s sleep
002 S last night did ya
003 S I don’t know Reg didn’t I no

In each extract Reg makes a statement, with a tag question at the end (highlighted in green). The structure of Reg’s turn gives Sarah the information and then Sarah is led into the reply, effectively scaffolding her participation. This is important because Sarah’s memory problems mean that she would often be unlikely to remember this information herself. Reg, therefore, gives the information in a way that does not draw attention to the fact she has forgotten. Indeed, in extract 16 it is clear that Sarah does not remember the night before, “I don’t know” (003), before providing an answer that is consistent with Reg’s assessment “didn’t I no” (003).

**4.4.5 Formulating and Delivering the Intervention**

Assessment indicated that whilst there were significant challenges in interaction and life in general, Sarah and Reg were managing relatively well. Reg had a good understanding of how best to manage Sarah’s communication needs and he displayed a remarkable level of patience, with a number of strategies to help them both cope. It appeared that Reg had naturally adapted and made many effective changes in the way he interacted with Sarah and so interaction-focussed therapy to
change interaction was unnecessary. The data had highlighted issues with a lack of conversation and repetitive topics and this therefore raised the issue of whether life story work could contribute to facilitating opportunities for enhanced and biographically orientated interaction. We agreed to spend time exploring memories and how these might be cued in life story work. This took up our next block of six visits from April to July 2013.

**Exploring Life Story Formats**

Sarah already had a printed and bound life story book and we looked through this on two occasions and one of these sessions I video recorded. Sarah now had difficulty recognising many of the photographs, even with the written word underneath. She did not, for example, recognise herself, Reg or her daughter without prompting. There were parts that elicited more conversation, but these were generally those areas we had already identified within our interviews, e.g. recounting the story of gaining her first job. There were parts of the book which no longer seemed to elicit any recognition or meaning for Sarah and therefore did not lead to conversation (an example of this is provided in Appendix 11, extract 17). It would seem that whilst the book had been useful at an earlier stage it was now limited in encouraging conversation.

On another occasion (22/7/13) I explored Sarah’s autobiographical memory further by using a life story template (‘Activities to Share’, no date available). Again, there were a few stories from her past that Sarah could tell in detail; however, there were many parts of her life that Sarah was unable to recall, even with explicit prompting from Reg. For example, she could tell a story about her daughter as a baby and would talk about her in the present, e.g. “our Harriet,” but Sarah had no recollections of her growing up, teenage years or her early adult life.

I began to explore other formats for life story work. A session using a sensory box, with a range of objects of various colours and textures that Sarah was reported to like, fell very flat (V 14/6/13). I considered investigating the effects of a memory box with Sarah’s own possessions, however I felt, due to reports from the family and my observations, that exploring songs and making a life story music DVD might be more successful.
Sarah’s daughter was also keen to be involved in the life story work and Harriet, Sarah, Reg and I began to draw together a list of songs that were meaningful to Sarah, either in the past or the present. I then played these songs to her using either a soundtrack or a video clip of the particular artist from ‘You Tube’, identifying the songs she particularly liked. Rather than just make a DVD of these artists, I wanted to involve the family in this activity, including clips of them singing together, because I felt this would be more engaging for them all to watch together later. We therefore organised an evening when Harriet and her husband were present and we video recorded a member of the family introducing each song, e.g. “We’ve chosen this song because we know you love RED” to introduce Chris De Burgh singing ‘The Lady in Red’. I also recorded Sarah singing with members of her family and this led to some moving and meaningful video footage. The following video recordings were all uploaded into ‘windows moviemaker’:

- Family members introducing the artists and stating why the song was meaningful.
- The artist singing.
- Family members singing with Sarah.

The videos were then organised appropriately with relevant title lines added on screen, e.g. the title of the DVD as an introduction (Thank You for the Music), family member’s names when they appeared on screen and linking title slides to give flow to the DVD, e.g. “and now for us all singing...(song name)”. Care was taken to ensure that videos were of a similar volume and fading was used to slowly fade in and fade out tracks. Where possible atypical words were spelt with a regular spelling, e.g. Cilla (Black) was spelt “Silla” on screen to help Sarah read them with her surface dyslexia. Finally, a credits slide listed the names of the family members who took part. The video was shown to Sarah on two occasions to pilot and refine the format, once on the laptop and once on the screen of her television and alterations were made as appropriate. This included:

- Ensuring labels of people’s names appeared on screen throughout (this reduced Sarah saying “who’s that?”)
• Altering the order of songs – ‘I like a nice cup of tea’ was initially first, however it led to Sarah requesting tea from Reg even if she has just had a cup and this was therefore placed at the end.
• Ensuring all lyrics of songs appeared at the bottom of the screen at the request of the family, so they could all sing along more easily.
• A particular song was omitted as this made Sarah’s daughter upset.

A final DVD was given with a cover using stills from the recording session and an explanation of life story work on the reverse (see Appendix 11 for a copy of this). Copies were given to Sarah and Reg and another to Harriet and her family.

4.4.6 Outcomes of Intervention
To explore the outcomes of the life story DVD intervention, I examined video and audio recordings of our session making the DVD and then two sessions with Sarah and Reg watching the piloted and final versions. My aim was to understand how the life story process and the completed product, contributed to Sarah’s interaction and well-being in the here and now, i.e. to undertake an in-the-moment qualitative evaluation of interaction.

The video and audio recordings were viewed on two occasions and recurrent features noted within the data. Extracts of the video recordings that illustrated these features were then chosen for more in-depth analysis. This involved transcription of singing and talking, alongside transcription of relevant nonverbal behaviours. These transcripts were then analysed in detail and collections of data illustrating recurring features were made. This method was therefore essentially that used within the conversation analysis in this study, with the song forming an additional part of the analysis, as if a speaker were present in the room. I will now present these features using this data. In the following extracts bold type is used for singing and standard type for talking. Behaviours occurring simultaneously are bracketed, as standard in conversation analysis, with additional spacing used to enhance the readability of the text, where necessarily. I have included still photographs taken from the video to illustrate important nonverbal aspects to the data. The following aspects will now be discussed:
1. **Distraction from distress**

2. **Facilitating interaction**
   a. In response to the lyrics
   b. Making up own lyrics
   c. Embodied emotional connections
   d. Arising from the video process or watching the DVD

3. **Performance and Identity**
   a. Embellishments and over-singing
   b. Embodied performance
   c. Reaction from her audience

**Area 1 - Distraction from Distress**

Engaging Sarah in song distracted her from her recurring worries about her headaches and requests for pain relief. The effects of this distraction were particularly dramatic during the session making the DVD (V 22/11/13). On this occasion Sarah was initially in bed, with her family present in the lounge. Reg asked her to get out of bed, as he thought it might distract her. However, sitting in the chair, she looked in pain and I thought we may have to postpone our filming. The music started and as the following extract shows, her face and body begin to change and in less than a minute she had begun to sing along and looked totally different.

**Extract 18) - Distraction from distress (V 22/11/13)**

Here Sarah (S) is with Harriet her daughter (H) on camera with Reg (R) in the background. Chris De Burgh starts playing on the laptop (M, for music). Line numbers are placed on the corresponding photograph, with time in seconds.

```
001  S  I’ve still got headache ((pointing to head not looking well at all))
002
```

001 (3 secs) headache
yeah ((music started))

I've never seen so many men ask you if you

((eyes shut rubbing forehead not well))

I've never seen so many men ask you if you

wanted to dance

((swaying to music))

They're looking for a little romance, given

((looks at computer . . . looks at Jackie))

half a chance, and I have never seen that

((looks at Reg, moves head to music, smiles))

dress you're wearing or the highlights in your
016 H dress you're wearing or the highlights in your
017 S ((looks round moving head slightly to music))
018 M hair that catch your eyes, I have been blind
019 H hair that catch your eyes, I have been blind
020 S ((looks at H, joint eye contact))

021 S yeah
022 M The lady in red
023 H The lady in red
024 S ((head back and forwards)) The lady in red

Sarah begins with complaining about her headache (line 001, photograph at 3 seconds). There is no eye contact, her eyes are shut (006) and she is not looking well (photograph at 9 seconds). However, she then looks at the laptop and then to Jackie, the researcher (011, photograph at 18 seconds), beginning to attend to the music. She then starts to move to the music (lines 014 and 017); she begins to smile (line 014, photograph at 23 seconds). By line 020 she is making eye contact with Harriet (photograph at 28 seconds) and then in line 024 she is singing along with her “the lady in red” (photograph at 33 seconds). By 54 seconds, she is happy and engaged in

At 54 secs singing, moving body: “oh yeah . . . the way I wanna be”
the song as evidenced by her voice, face and body movements (photograph at 54 seconds). This level of engagement continues throughout this song.

During this session Sarah did not ask for headache tablets while the music was playing but when the music had stopped, she started to complain about her head and ask for tablets. At a later visit (26/02/14), I noted that Sarah was again repeatedly asking for headache tablets in the first hour, rarely going more than five minutes between requests. However, whilst watching the 40 minutes of the DVD she did not request any tablets. The DVD did not eliminate all repetitive behaviours and routines, as Sarah often still asked for food, cups of tea and chewing gum. It would seem, therefore, that music appeared to lift her mood and distract her from her worries, rather than reduce all routine behaviours.

**Area 2 - Facilitating Interaction**

There were a number of ways that the DVD facilitated interaction as I now illustrate.

**a) In response to the lyrics**

The following extract illustrates that Sarah did not just sing the lyrics of the songs, at an automatic or perhaps ‘over-learnt’ manner; she processed the meaning and used this to interact with others.

**Extract 19) - Interaction arising from lyrics (V 22/11/13)**

Here Harriet and Sarah are singing to a Tina Turner song, ‘Simply the Best’ (M = music).

<table>
<thead>
<tr>
<th>Time</th>
<th>Role</th>
<th>Line</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>M</td>
<td>[tear us apart]</td>
</tr>
<tr>
<td>002</td>
<td>H</td>
<td>[tear us apart]</td>
</tr>
<tr>
<td>003</td>
<td>S</td>
<td>((looks at H)) no [no no] no chance no chance</td>
</tr>
<tr>
<td>004</td>
<td>H</td>
<td>no no</td>
</tr>
<tr>
<td>005</td>
<td>M</td>
<td>baby I would rather be [dead]</td>
</tr>
<tr>
<td>006</td>
<td>S</td>
<td>[dead] no no we don’t want to die yet do we</td>
</tr>
</tbody>
</table>

In response to the lyric “tear us apart,” Sarah looks to Harriet in line 003 and expresses her disagreement with that possibility: “no” and “no chance.” Harriet also expresses “no” as they look at each other. Following the lyric “I would rather be
dead” Sarah says to Harriet “we don’t want to die yet do we?” In these exchanges we therefore see a strong connection between Sarah and Harriet, initiated by Sarah, talking between and arising from the lyrics. The result is both affectionate and humorous. Another example is provided in Appendix 11 (extract 20).

b) Making up Own Lyrics
Sarah would sometimes make up her own lyrics, singing in tune to the music, but with her own words. An example of this is provided in Appendix 11 where in tune and time to Tina Turner Sarah sings to Harriet to say she loves her.

c) Embodied emotional Connections
Connections between family members were not just verbal but also embodied. The Cilla Black song, ‘You are my World’, is Sarah and Reg’s engagement song that Sarah sung to Reg on the night they got engaged at a family party. Sarah no longer remembers this association with the song but she does still remember many of the lyrics and its distinctive tempo. On the two occasions this song is on video, Sarah is seen to reach for Reg’s hand when singing “my arms reach out to you for love” (in extracts 22 and 23) thus demonstrating an embodied connection with him.

Extract 22) - Embodied connection - engagement song 1 (V 22/11/13)
This example is from our session making the DVD.

```
001 M  So my arms reach out to you for love
002 S  So my arms reach out to you for love
003    ([reaches over to Reg takes his hand])
004 R  ([takes Sarah’s hand, smiling])
```

002 – “reach out to you”
002-004 – “... for love.”
Extract 23) - Embodied connection - engagement song 2 (V 6/01/14).

This example is from one of our session watching the DVD.

| 001 M | [So my arms reach out to you for love] |
| 002 S | [So my arms reach out to you for love] |
| 003 R | ((reaches over to Reg takes his hand)) |
| 004 R | ((looks at Sarah, takes her hand)) |

002 – “reach out to you” 002-004 – “... for love.”

The behaviours on both videos are remarkably similar, with Sarah and Reg holding hands while Sarah sings. Sarah also makes embodied connections with Harriet (see extract 24 in Appendix 11) and there is a particularly poignant exchange between Sarah and Harriet when making the DVD (V 22/11/13), at the end of ‘the Lady in Red’:

Extract 25) - Emotional connection (V 22/11/13)

| 001 M | my lady in [red] |
| 002 S | ↑ [reː] eːd |
| 003 H | I love you ((leans in joint eye contact)) |
| 004 S | I love you darlin’ I love you so: much |

In my field notes during the assessment phase I did not record such displays of affection within casual conversation.

d) Interaction Arising from Making or Watching the DVD

Sarah regularly commented on the video, or about seeing herself and her family on screen, e.g. “I love red [reading off screen] I do, I do love it”; “my baby girl” [Harriet on screen]. She often seemed surprised to see her family on television (V 6/01/14), photo 1 below, and this quickly turned to delight, photo 2, taken seconds later.
When watching the DVD Sarah repeatedly asked “who’s put me on telly Reg?” with amazement and delight, but was unable to retain any explanation as to why we had made the DVD. Reg and I decided that saying it was because she had a good voice was the most easily understandable and helpful for her, as it reinforced a positive aspect of her retained identity, i.e. that of being a good singer.

**Area 3 - Performance and Identity**

It was clear from talking to Sarah that being ‘a singer’ was an extremely important and distinct part to her identity that she still retained, as she explained when watching the DVD (V 6/01/14): “you’ve not been a singer really have you Reg, I’ve always been a singer, I remember when I was as I child when me mum was here”.

The video illustrates that Sarah does not just sing, but she is seen to perform with the following aspects contributing to this sense of performance.

**a) Embellishments and ‘Over-Singing’**

There are numerous examples of Sarah creatively adding extra notes, pitch rises and falls and singing extra items such as “oh yeah” as a professional performer might do.

**Extract 26) - Over-singing (V 22/11/13)**

In this example Harriet and Sarah are singing to ‘Simply the Best’

```
001 M     in your heart I see
002 M     [the star of every night and every day]
003 H     [the star of every night and every day]
004 S     [every day]
005 S     woo ooo ooo o↑o↓o
```
In line 042 the music plays (no lyrics) and Sarah sings along to the rhythm and tune with varying pitch (see Appendix 11 for another example, extract 27).

b) Embodied Performance
Across the data Sarah is observed to move along to the music. These movements seem less about communicating to others but more about her natural and unintended response to the music, as extract 28 illustrates.

**Extract 28) - Embodied performance 1 (V 22/11/13)**
Here when singing to ‘Simply the Best’ with Harriet, Sarah holds out her hands much as a singer would do when performing (see photo and lines 003-004)

001 M [better than all the rest]
002 H [better than [all the rest]
003 S [all the rest]
004 ((two palms held out))

See Appendix 11 for two further examples of this (extracts 29 and 30).

c) Reaction from ‘her audience’
Sarah’s sense of performance is added to by the reaction of those around her. She is the centre of attention when making the DVD and when watching it, her family and the researcher comment positively about her singing and encourage her to perform as extract 31 illustrates.

**Extract 31 - Audience reaction 1 (V 22/11/13)**
At a rather flamboyant end to ‘the Lady in Red,’ Reg comments positively on Sarah’s performance (003):
In other instances family members clap her performance and when watching herself Sarah also indicates approval by clapping (see Appendix 11 for extracts 32 and 33 illustrating this). In this way there is evidence of Sarah ‘reliving the moment’ with approval of her own singing abilities.

**4.4.7 Summary – Outcomes of Life Story DVD**

Whilst the life story book and ‘feely box’ had limited success at this point in time in terms of encouraging conversation, the life story DVD had many positive effects for interaction. Familiar and meaningful music had the power to engage Sarah verbally and nonverbally with her family and distract her from her current distress. Sarah was able to depict her identity as a competent singer through song and embodied performance. In-the-moment analysis of the video data sees Sarah take an active part in both the process of making the DVD and in her reactions when watching it. The process and the final product were shown to elicit a number of important behaviours that contributed to her identity and sense of wellbeing. In this way the intervention was able to enhance Sarah’s abilities and participation within interaction in a way that by-passed her difficulties with conversation.

Sarah and her family (Reg, daughter, son-in-law and grandchildren) had watched the DVD over Christmas and they had enjoyed this and were very happy with the DVD (F 31/01/14). It had also been shown to others visiting the house including Reg’s relatives, their neighbour, the community nurse and their support worker. They had developed a family joke teasing each other about who was the best singer “on that TV”. The process had led to other activities with their son-in-law making Sarah another DVD with another set of favourite songs (F 31/01/14). Harriet in particular, however, reported that whilst it was lovely to see her mum happy, sometimes when making the DVD, it also made her sad as it reminded her of how her mum used to be in the past and she compared this to how she was now, saying: “sometimes happy memories can also make you sad” (F 31/01/14). Reg reported a similar feeling, though perhaps to a lesser intensity.
A telephone call on the 29th August 2014, six months after they had received the DVD, revealed that they still enjoyed watching it together, with Reg reporting “I’m surprised it’s not worn out, the amount of times she’s seen it” (T 29/08/14).

4.4.8 Reflections on the Intervention
As I have illustrated, these two first case studies presented with different challenges for intervention, arising not just from the language disorder present in semantic dementia but also arising from differences in adaptation to the changes in conversation and the support structures around them, both impacting on intervention. Whilst interaction-focussed therapy was necessary for Peter and Joanna, changing patterns of interaction was not required in Sarah and Reg’s situation; however, life story work was appropriate in this case to foster opportunities for interaction using Sarah’s long standing love of music.

4.4.9 Concluding Contact and Further Needs
Sarah and Reg had a good care plan and I was confident that they would be well supported over the challenges that lay ahead for them both. Reg phoned me in August 2014 because he had seen a programme on television about music and dementia and he wanted to tell me about it, saying our DVD was better! In March 2015 he phoned to say Sarah had a fall and it had been difficult to regain her mobility and she had been admitted to a care home. We talked about impressing on the home her love of music. As always Reg remained positive, despite the situation.

4.5 Case Study 3 - Doug and Karina

4.5.1 Introduction
I will now present the third case study, Doug and Karina, a married couple who had taken part in an earlier study on semantic dementia in 2010 which formed part of my Masters in Clinical Research study (Kindell, 2011) and two published papers (Kindell et al., 2013; Kindell et al., 2014b). The research reported here began in the summer of 2013 and required additional ethical approval from the appropriate research governing body and agreement from the family to reveal the link between these two studies (see Appendix 5 for further details). In 2010 Doug was using a
regular practice of enacting scenes in his talk, using dialogue in the form of direct reported speech along with use of body movement and facial expression (Kindell et al., 2013). Karina had displayed a good understanding of Doug’s communication needs with ‘making connections’ presenting as an important theme for the family, describing their attempts to keep Doug included in family life (Kindell et al., 2014). This earlier study was not a therapy study, but the video data and results were explored with the family and they found this helpful in finding meaning in his behaviour (Kindell et al., 2014); for example, noting how much Doug was ‘in the scene’ when using his enactment.

In the later encounters, reported here, Doug’s communication difficulties had progressed. However, despite presenting as the individual with the most advanced semantic dementia in this study, there were still striking islands of skill within his interaction and Karina continued to include Doug in the conversation. Events overtook our work, in that Doug was admitted to long term care in November 2013. The focus of the intervention then became the production of relevant and useable information for the care home, using knowledge about Doug’s interaction, to help staff connect with Doug and include him in the social life of the care home.

4.5.2 Background
By 2013, Doug and Karina were both 73 years old and had been married for 48 years. They had two grown up children, a son, Stuart, who lived locally and a daughter, Nicola, who lived abroad. Doug was a retired lecturer of engineering at a local college, whilst Karina still ran a business from home. Doug had been diagnosed with semantic dementia in 2006 after a number of years of word finding difficulties; first noticing changes in 2000 in remembering the names of the students he taught. Over the years there had been a slow decline in Doug’s language skills and his ability to engage in activities of daily living. By 2013, Doug was still fit and mobile but needed Karina to organise and prompt him with all activities of daily living.

4.5.3 Our Initial Encounter
Visiting in June and July 2013, I was struck by the progression in Doug’s symptoms since I had last seen him. In 2010 most of his speech had been English words, now
there were neologisms and repetitive syllables, e.g. “dadadadadad” making it harder to understand him. Doug would, however, still attempt to communicate, as I record:

\[
He \text{ joins in the conversation with comments like ‘brilliant’ or ‘oh yes’ and then sometimes the odd extended bit of talk. His speech is now very hard to follow but he still has good eye contact, smiles broadly and seems very sensitive to the emotion of the moment, often mirroring that (F 12/07/13).}
\]

Doug attended day care six days in the week leaving only one day free for all appointments and so research visits were booked once a month over a nine month period from July 2013 to January 2014.

4.5.4 Establishing a Baseline – Assessment

Assessments took place over five visits from July to October 2013 and Doug was admitted to the care home in November 2013, as summarised in Table 4.5.

**Semi-Structured and Structured Interviews**

Karina reported that Doug’s dementia had progressed since we last met and she was beginning to feel the strain, particularly around issues of toileting and getting up repeatedly at night. Karina’s overall score using the Care-giving Burden Scale was 5/13 (Gerritsen & van der Ende, 1994). Whilst Karina was happy to chat about their situation, she found completing questionnaires stressful, refusing to complete the DEMQOL-Proxy (Smith et al., 2005).

<table>
<thead>
<tr>
<th>Session Number</th>
<th>Date</th>
<th>Main activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14/06/13</td>
<td>Discussion of study</td>
</tr>
<tr>
<td>2</td>
<td>12/07/13</td>
<td>Consent and initial interview using video</td>
</tr>
<tr>
<td>3</td>
<td>16/08/13</td>
<td>Semi-structured interview with Doug and Karina</td>
</tr>
<tr>
<td>4</td>
<td>05/09/13</td>
<td>CAPPCI interview</td>
</tr>
<tr>
<td>5</td>
<td>04/10/13</td>
<td>CAPPCI interview</td>
</tr>
<tr>
<td>6</td>
<td>24/10/13</td>
<td>Video of Doug and Karina looking through his life story book</td>
</tr>
<tr>
<td>7</td>
<td>22/11/13</td>
<td>Doug admitted to care – ‘Making Connections’ summary sheet</td>
</tr>
<tr>
<td>8</td>
<td>20/12/13</td>
<td>Visit to Karina</td>
</tr>
<tr>
<td>9</td>
<td>17/01/14</td>
<td>Visit to Karina to conclude the research</td>
</tr>
</tbody>
</table>
At both our past interviews and during this encounter, Karina indicated that Doug’s personality had changed significantly. He was now less serious and his interests had changed, for example, his hobby of stamp collecting held no interest for him now, despite taking up a large part of his adult life (I 4/10/13). He now liked to sing and dance something that was completely out of character for him as Karina reveals:

_He can't wait to dance. You know, the dance thing is just incredible . . . I watched him the other day, they were doing the conga round the room, and [another carer said] ‘gosh, you know, Doug's got such good rhythm, did he always like dancing?’ ‘No!’ But he has. And then, he will also sing songs_ (I 04/10/13).

Whilst Doug now loved to dance, Karina said it was not something that he ever talked about: “_The very favourite thing he likes doing now is the dancing, but I don’t think he uses it as a topic. He doesn’t talk about that_” (I 05/09/13).

**Interviews about Conversation and Analysis of Video Data**

Full scores for the CAPPCI (Perkins et al., 1997) are reported in Appendix 12. When interviewed about Doug’s communication, Karina reported that she still tried to keep him involved:

_I do try conversations, even though I know I may not get the response. I still think it’s better to talk about things . . . I say you know, I went today to see so-and-so, and the traffic coming back was really terrible. I don’t expect a response, it’s just I’m communicating, rather than leave it silent_ (I 05/09/13).

Karina reported that Doug no longer struggled to find words, but that his speech did not always make sense to her. However, Karina reported: “_there is still a way to communicate. He’s not completely cut off . . . You’ve got the body language and the facial expressions and things to go with it haven’t you [turning to Doug]?_” (I 05/09/13). Karina often spoke about the importance of nonverbal communication including facial expression; she reported that he glared at her when he was not happy and then added: “_probably left over from teaching . . . he was very good at teacher glare_” (I 05/09/13).
Doug could no longer introduce topics, as Karina put it: “I don’t think he’s got the language ability to have a new topic” (I 05/09/13). Therefore, most of their talk was fleeting with a focus on the here and now or recent events, as Karina illustrates:

But it’s very short interaction things. Because there’s not a lot we can interact about really. If I ask him, when I pick him up from [day centre], was it a good day? ‘Mm’. Were there lots of people there? I’ll get something about that, but it doesn’t always make sense (I 05/09/13).

In certain circumstances the lack of a precise response was, however, problematic; for example, when Doug was unwell recently it was hard for both Karina and the doctor to ascertain the problem (I 12/07/13). Karina reported that there were instances when Doug’s speech was surprisingly clear: “And sometimes you get a perfectly normally formed sentence, and you’re ‘whoa’. Stuart was over here for dinner, and he put Doug’s dinner down for him and said ‘pour vous’ and Doug said ‘gracias’” (I 05/09/13). Karina reported increasing problems with Doug’s understanding, particularly if the response required him to physically do something in response to an instruction (I 05/09/13).

Karina had found video recording on their own challenging, as I recorded in my field notes: They do not talk at meals like they used to and so she said she had tried to move the camera about a bit and she was not sure how helpful this had been (F 5/9/13). Karina had recorded Doug shaving and an interaction with him changing his shoes. Doug’s comprehension problems are clear during these encounters, for example, verbal prompting alone is no long sufficient, Karina needs to physically guide Doug (a summary of the video data is provided in Appendix 12).

I used transcripts from a video (12/07/13) and an audio recording (16/08/13) with all three of us in conversation together to further explore Doug’s communication. These two data sets, one hour 32 minutes in total, were used because Doug is actively engaged in the conversation with us, including a number of sequences of extended talk from him. There are three areas I will now outline in turn that are of note:

- Tag questions.
- Test questions.
Performance.

I have chosen to transcribe those ‘non-words’ used by Doug in standard English phonetic spelling as close as possible to the target, rather than transcribe using the International Phonetic Alphabet, in order to make the extracts more accessible.

**Issue One - Tag Questions**

Karina had a recurring practice whereby she gave Doug a piece of information and then finished off with a tag question. This is the same practice Reg used with Sarah, in case study two and, like Reg, this seemed to be Karina’s way of deliberately drawing Doug into the conversation. This practice is illustrated in the following two extracts. In each, Karina makes a statement about recent events, followed by a tag question highlighted in green. In each extract Doug is drawn into the conversation, agreeing with Karina’s statement, although it is unclear as to whether Doug actually remembers these events.

**Extract 34) - Tag question 1 (V 12/07/13)**

001 K they gave you beer didn’t they at the day
002 centre one day didn’t you you had some beer
003 all the men had a beer didn’t they
004 D oh that’s right yes yes tiddly

**Extract 35) - Tag question 2 (V 16/08/13)**

001 K because Paul Brown came to see us didn’t he
002 D oh yeah

**Issue Two - Test Questions**

Below, extract 36 (about a recent event) and extract 37 (a regular joke they tell) illustrate another recurring practice whereby Karina used ‘test questions’ with Doug, i.e. she asked a question to which she already knew the answer (lines 001-002 in yellow). Unlike the pattern evident with Peter and Joanna, if Doug was unable to answer the test question, then Karina quickly provided the required response (line 004 in each). The test question appears to follow a similar function to tag questions in that it provides a slot to draw Doug into the conversation and, moreover, because the information is already known to Karina, when Doug is unable to provide it (003),
Karina can give the information and progress the interaction. Karina’s use of test questions is, therefore, similar to the practice used by Reg in the previous case study.

**Extract 36) - Test question 1 (12/07/13)**

001 K and what did we have for lunch can you remember
002 D American lunch we had
003 D I can’t really remember it
004 K hot dogs
005 D hot dogs was it
006 K and donuts

**Extract 37) - Test question 2 (12/07/13)**

001 K Jim what does Jim always say that makes you laugh
002 D oh I can’t remember
003 D remember excuse me would you ring my wife
004 K ((in a posh voice))
005 D hhhhh that one yeah

**Issue Three - Performance**

There were a number of instances in the data when Doug would become animated and give an extended response with active movements of his arms and face, singing lines of his talk, acting out snippets of conversation with direct reported speech and, at times, acting out an upper class accent. Extract 38 below illustrates this with another example, extract 39, given in Appendix 12. On the one hand, Doug continues to use enactment in his talk as described previously (Kindell et al., 2013). On the other hand, the decline in his language skills makes these harder to follow. In addition, Doug appears to be using other forms of performance with more singing evident in his talk along with body movement. Such performances seem to have a structure, often with a clear end with a clap, a stamp of his foot or a throwing gesture, as the following, extract 38, illustrates:

**Extract 38 - Posh voice (12/07/13)**

In a number of extracts Doug is observed to act out a convincing upper class accent to display the talk of another person, manipulating the phonetic aspects of speech (including extended vowel sounds) and along with this he uses exaggerated gesture and facial expression, giving a convincing performance. Here, Karina has again been joking about Jim, their friend, and this leads Doug to act out a posh voice (in bold).
In this sequence Doug appears to be acting out talking to at least one other person, reminiscent of his previous enactment behaviours. Doug’s performance ends very definitely in lines 009-010 with a spoken: “thank you tush tush” and a definite throwing gesture. I summarise this with “off you go” (012). This ‘posh voice’ (as Karina described it) represents a surprisingly high level skill with language given Doug’s degree of semantic dementia. Karina goes on to explain that Doug’s mother often said: “[Doug] went to Miss Mary Mark-Brown’s Pre Preparatory School [in an upper class accent]” making Doug laugh. His mother’s assertion that the family were of a distinguished class was a running joke in the family, often acted out with this accent. Karina believes that this accent in Doug now can be tracked back to his mother (I 12/07/13).

**Video Data - Doug’s Life Story Book**

Doug had a life story book although Karina reported that he did not take much interest in the book these days. I video recorded Doug looking through this book with Karina to examine the impact on interaction (V 23/10/13). This session was transcribed in a standard interview format and then the first 20:52 minutes were additionally refined using conversation analysis transcription. Both the initial interview and the conversation analysis transcript were analysed using NVivo 10 to identify recurring issues in the conversation.

At the start of the session Doug’s mood was good and he attempted to engage with Karina, looking at both her and the book. It became apparent that Doug had difficulty recognising many of the photographs including those of him and close
family. He held the book close to see the pictures because he now refused to wear his spectacles. The addition of the written word underneath did not aid recognition (extract 40, contained in Appendix, 12 illustrates this). Difficulty recognising and finding materials meaningful was also evident with other stimuli, such as memorabilia and maps, here for example from his past hobby of stamp collecting:

Extract 41) - Stamp collection (V 24/10/13)

001 K now that is a country down there called India
002 D do you remember something about India ((points to picture of map))
003 K no you can’t remember you’ve not been there
004 D no
005 K you used to collect the stamps from there
006 D oh tis m ((flat intonation))
007 K from India because you liked collecting Indian
008 D stamps
009 K yes I did yes ((flat intonation))

In lines 006 and 011 Doug’s responses were appropriate, e.g. he agreed that he liked collecting stamps from India (011). However, his flat intonation in these responses is in contrast to topics that engaged him and may indicate Doug’s lack of full recognition of this topic and certainly not the passion for stamps he had in the past. Karina tried unsuccessfully to prompt Doug to recall something from the period in time associated with the picture, e.g. “do you remember something about India” (002), followed by directly giving him the information: “you used to collect the stamps from there” (007). Neither leads to any convincing reaction or recognition from Doug.

This lack of recognition was apparent with pictures and information from a variety of topics including: where he lived and the school he went to as a child, his grandparents, marriage to Karina, his own children, his work (including some striking past relationships), hobbies, social events, parties and funny stories from the past. Although he was not able to recognise pictures of his mum and dad, the spoken words ‘mum’ and ‘dad’ appeared to have some resonance for him in that he would immediately react using changes in facial expression and intonation.
There was only one picture that Doug unequivocally recognised and was able to convey who it was and this was a picture of himself in his Navy uniform as this extract illustrates:

**Extract 42 - The Navy 1 (V 24/10/13)**

001 K who’s that
002 D that’s nice *(pointing to page)*
003 K who is it
004 D that one’s nice
005 K but who is it
006 D *me hhhh* *(looks at Jackie)*
007 K yes it is

Although Doug’s language difficulties made it hard to follow his talking, other pictures of the Navy also seemed to engage him. Fragments of talk, along with his behaviour, appeared to indicate at least some recognition of the words and/or pictures involved (see Appendix 12 for extracts 43 and 44 to further illustrate this).

Whilst Doug’s mood was good at the start of the session, there was a gradual change during this activity. There were instances of frustration when Karina tried to encourage him to remember more, as the following extract illustrates:

**Extract 45 - Getting frustrated (V 24/10/13)**

Karina asked Doug what he remembered from battles in the Navy. Doug gives an extended response (002-005, in yellow) indicating he does not know and is frustrated:

001 K can you remember anything about either
002 D if I had that hand *(pointing in front of him)*
003 I can tell you *(push away gesture)* but I can’t you tell me because I can’t bloody know
004 what it’s all along now

After 20 minutes looking through the book Doug becomes first a little restless and then begins with more rapid breathing that can be observed to come and go (27:20, 28:15 and 30:04 minutes). He eventually begins to look tired and unhappy and Karina and I agreed to stop the activity (33.14 minutes).

At this point Karina and I discussed why Doug had become agitated. Doug denied that he needed the toilet. He may have been tired although he was usually able to
interact in other interviews for well over an hour. Karina wondered: “The other thing I’ve noticed, now he’s stopped, is I kept asking questions, what is? Who’s that? Didn’t I? Did you feel as though you were in an exam? [D: Yes].” At the time and examining the video since, I did not feel that Karina had much option than to ask questions because Doug was not responding to the pictures himself, either verbally, or through reaction, e.g. ‘ah!’ Karina was therefore left to try to draw conversation from him and if he did not respond, she was quick to provide the information. Karina and I agreed that the Navy still appeared to be a consistent topic to spark Doug’s interest. Karina demonstrated that even when Doug could no longer access the word ‘Navy,’ he used a consistent gesture to convey it: “you see because we always used to remember the Navy didn’t we [Karina does up and down sea gesture]” (I 24/11/13).

4.5.5 Formulating and Delivering the Intervention

I have illustrated that despite Doug’s significant difficulties with language, he retained many skills with respect to interaction: he took turns at talk, used good eye contact, facial expression and joined in with relevant comments when he could. Karina understood this well and encouraged him to take part at a simple and achievable level. Interestingly when asked whether Doug started up conversations Karina replied: “it depends what you mean by conversations” (I 4/10/13). When asked what we should call Doug’s communication she reasoned:

Interactions rather than conversations, isn't it, whether they mean something to him but don't mean anything to the other person . . . now, I think he does have interactions rather than conversations . . . because he's communicating with people and, you know, enjoying communication, aren't you? (I 4/10/13)

To Karina the word ‘conversation’ appeared rather problematic to apply to Doug, whilst ‘interaction’ felt less constraining. Examining the video and at observation, in my clinical opinion, I felt that interaction-focussed work to change interaction patterns was not indicated as they were managing well. Clearly, life story work to increase opportunities for interaction was not as simple as trying to encourage past interests using pictures or memorabilia. Doug’s life-long passion for stamp collecting had gone. His new interest of dancing had no particular relevance in the
past and did not appear to be a relevant topic for conversation for him; however, participating in the activity itself was highly important.

Events overtook us in that by my seventh visit on the 22\textsuperscript{nd} November 2013, Doug had been admitted to a care home for emergency respite, a few days earlier, with a view to long term care. The original ethical approval for this project did not include working with other agencies outside of the family. Therefore, Karina and I decided the best course of action was for us to work together to produce accessible information that Karina could explain to the home to encourage them to interact with Doug appropriately. We both agreed that the life story book was useful to tell others about the life Doug had lived, so they could see beyond the semantic dementia to all that he had done and achieved over the years. However, apart from the pages about the Navy, the book was no longer a reliable aid to support Doug’s interaction in the ‘here and now’. Put simply, most of the topics in the book appeared not to hold any meaning for Doug and those things that currently engaged him in interaction could not be displayed in picture format because such experiences were embodied, for example, dance, his response to humour and his uncanny ability to do a ‘posh voice’.

Karina and I agreed to develop a one page summary sheet focussed on unique ways of ‘making connections’ with Doug, see Figure 4.3. We reflected on Doug’s interaction, the assessments so far and agreed the relevant information for this exercise. We aimed to encourage the care staff to understand and value Doug’s abilities with nonverbal communication and the importance of moving beyond information exchange, to facilitate interaction, activity and social connections. Therefore, rather than being an advice sheet on communication, also included were those things that Doug liked to do: dance, conduct to music (sometimes with a wooden spoon in hand), watch his favourite DVDs and walk about. Doug’s ability to do a ‘posh voice’ was included because this was a memorable skill that could be easily facilitated in social interaction. We included past information only if it had a current relevance, so Doug did still respond to the picture of himself in his Navy uniform and he liked to look at pictures of boats, planes and transport. The fact he worked as a college teacher was relevant because Karina felt he had retained ‘teacher glare’ as discussed above, as were the names of Karina and his children as he still recognised these. Lastly, Karina was keen that we also include a line about Doug’s
love of carbohydrate rich food as he had gone through a period of very significant
weight loss at home a few years previously and that this could be an issue for the
care home too. I made the sheet and sent it to Karina to take to the home.

Figure 4.3 - Doug’s A4 sheet - Making Connections

<table>
<thead>
<tr>
<th>I enjoy interaction and using my good nonverbal skills. The words do not have to make sense it's the social connections that are important to me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes I might not understand and so it's helpful if you show me as well as tell me.</td>
</tr>
<tr>
<td>I like to keep active, to stand and walk about.</td>
</tr>
<tr>
<td>I was in the Navy. I like looking at pictures of boats, planes and transport.</td>
</tr>
<tr>
<td>I can do a great posh voice, ask me about it!</td>
</tr>
<tr>
<td>I love music: big band, swing, crooners…</td>
</tr>
<tr>
<td>Picture of Doug in the Navy</td>
</tr>
<tr>
<td>I particularly like sweet food and carbohydrates, all good for energy for me.</td>
</tr>
<tr>
<td>I like to watch DVD’s of Harry Potter, Sharpe… ask Karina about me!</td>
</tr>
<tr>
<td>I worked as a college teacher.</td>
</tr>
<tr>
<td>Karina and I have two children, Stuart and Nicola</td>
</tr>
</tbody>
</table>

4.5.6 Outcomes of Intervention

The ‘Making Connections’ sheet, produced in therapy, illustrated important aspects
of Doug’s interaction currently relevant to his care derived from analysis of his
behaviour through direct observation and from interviews. This intervention was
reacting to circumstance, i.e. the need to relay information to the home to help
Doug’s transition into care. Analysing interaction and outcomes outside of the home
was not part of the original focus or ethical approval for this study and therefore
evaluating whether the sheet was helpful for the care staff was beyond this study. Therefore a lack of evidence of outcomes related to the care home environment is a significant limitation to this case study.

Whilst I did not systematically examine if engaging in the life story process had any effect on Karina emotionally, the data indicate that attention to such issues would be useful in future research for family carers at such points of care transition. I had audiotaped and had transcribed our session on the 22nd November 2014 when Doug had just been admitted to the care home and reviewing this and my field notes indicates that Karina was, understandably, distressed at this time. She expressed many worries including whether the home was the right place for Doug, whether there were other care options and about the financial process involved. In my field notes I recorded:

Karina was more stressed than usual as things seemed to all happen very quickly for her. She was talking a lot about all the different possibilities . . . I wondered how realistic some of her expectations were and at times it felt like we were going round in circles with our discussions (F 21/11/13).

Whilst analysing previous interviews I had been struck by Karina’s ability to adapt to Doug’s condition, with a predominance of coding her responses as ‘adaptable and flexible’. This interview was different, in that I coded many of her responses under ‘barriers to adaptation’ as she seemed overwhelmed emotionally and practically, even with basic decisions. Reflecting on this session whilst analysing this data, it seemed that developing the ‘Making Connections’ sheet gave me, as a practitioner-researcher, a concrete structure to help regain some focus within this session and helped Karina directly engage in a purposeful activity to help Doug, at a time when she was feeling overwhelmed. At a later interview Karina remarked about how difficult she had found things at this time:

I couldn’t concentrate or function on one particular thing because I mean [the social worker] was saying I didn’t fill the [financial] form in when I should have filled it in . . . I found it very difficult to come back to the here and now and think, well, I’ll concentrate on that and concentrate on that (I 14/01/14).
The process also gave Karina the tools to open up discussions with the home about things that she was anxious to raise for fear of being critical, for example, she was concerned that Doug, as a big man, needed bigger portions: “I’m a little bit concerned, because I don’t want to criticise and say, you know, this isn’t right or whatever. But it is geared . . . to that particular group of sweet little old ladies more than anything” (I 22/11/13). We had discussed in detail during the session how Karina could raise this with the home, using the sheet, without it sounding like a criticism (I 22/11/13). At my next visit Karina reported that she had given the ‘Making Connections’ sheet to the care staff and had talked to them about the information, including his dietary needs (F 20/12/13). She was also able to tell them about the music Doug liked and she took in some of his music. The home agreed to put Doug’s music on the CD player in the quiet lounge and he could dance or conduct as he wished.

4.5.7 Reflections on the Intervention

Whilst Peter in case study one responded well to the information contained in his life story books, the evidence from Sarah, in case study two and now Doug is rather different. This indicates that a traditional life story book, even one directly made with the person with semantic dementia, may have limitations as a tool to encourage conversation for some individuals in the later stages of semantic dementia. In both Sarah and Doug’s cases studies I have illustrated using conversation data that many past interests and topics of conversation contained within the books appeared to hold no recognition or relevance. This indicates the dynamic nature of life story work in semantic dementia and, in common with much of dementia care, the requirement for interventions to be adapted as the person’s needs change.

Again, in Doug’s case, as with Sarah, music and dancing were a recurring theme; however, in this case these were newly acquired interests and seemingly at odds with Doug’s past personality and concerns. The focus was more on ‘doing’ than ‘talking’ and in doing enjoyable activities with others, such as singing and dancing, interaction occurred in that moment. Therefore, this and other aspects of the life story work focussed not so much on topics of conversation, but more on embodied skills that encouraged behaviours such as body movement, rhythm and facial
expression. Karina’s notion that for Doug it was less about conversation and more about interaction appears particularly helpful for people in the later stages of all types of dementia.

Doug’s case also illustrates that even people in the later stages of semantic dementia, may display surprising abilities that test current representations of the condition. At our interview Karina and I discussed how Doug had retained aspects of the concept of ‘posh’ in order to depict this concept in his talking and how surprising this may be, given the late stage of his condition, the help he requires with nearly all activities of daily living and the relative social complexity of this concept. Karina comments:

no there are bits there that are . . . I think, you know, pathways not pathways, somehow isn’t there and I imagine there’s little things being cut off somewhere and other ones that are still going through (I 16/08/13).

Karina’s comment makes some sense of this behaviour in lay terms. This clear island of skill, within otherwise highly compromised cognitive ability, illustrates that there is much to learn about why, at an individual level, some connections still appear to be there and some do not. Karina’s view that this skill can be traced back to Doug’s mother and the longstanding family joke about being ‘posh’ is a potentially intriguing idea, linking this specific behaviour to retention of personal knowledge from Doug’s past.

4.5.8 Concluding Contact and Future Needs

Karina and I spent my last visit discussing how she was coming to terms with Doug’s move to the care home. Despite her initial anxieties, she was now happy that Doug was settled and we go on to conclude:

J Right, so they seem to be doing everything, all the things we put on that little sheet, don’t they?

K Yes, absolutely.

J And they seem to have got to know his little ways.

K Yeah, one of the girls puts his music on and they have a dance (I 14/01/14).
Karina continued to keep in contact via email and telephone. During the early part of 2014 Doug settled well and remained at the care home and Karina was happy with the care provided. Sadly, Doug passed away in September 2014, after a short stay in hospital. The minister used Doug’s life story book within the funeral service to illustrate the varied life Doug had lived. At the time of writing, Karina was attempting to slowly rebuild her life without Doug. She keeps herself busy with her business and with another carer has taken an active role in a local carers group.

4.6 Case Study 4 – Ruby and Brian

4.6.1 Introduction

I will now present my fourth case study, Ruby and Brian, a married couple. Ruby had been diagnosed with semantic dementia five months before we met. Ruby and Brian were keen to engage in the life story work but did not wish to video themselves at the start of therapy, so interaction-focused therapy, as envisaged in the protocol, was not possible. Ruby was earlier in the course of semantic dementia than the three cases I have so far presented and the challenges arising from her conversation were, in some respects, different. In addition, Ruby and Brian were in the process of coming to terms with the diagnosis and the implications of this, including issues of disclosure of her diagnosis to others and this impacted on issues of interaction. I will discuss the life story work, in terms of managing conversations and including how this was tailored to Ruby’s situation.

4.6.2 Background

Ruby (age 71 years) and Brian (74 years) were referred into this study by Ruby’s memory clinic nurse. They had been married for 52 years and had two sons and seven grandchildren, but their daughter had sadly passed away. They had both grown up in the local area and had a wide circle of friends that they liked to meet up with in the early evening or at the weekend for a drink and a chat. Ruby had married Brian when she was 19 years old and, apart from the odd part time job, had focussed her attention on bringing up her children and taking care of the house, as Brian had often worked away.
4.6.3 Our Initial Encounters

Ruby and Brian were very welcoming, coming to the front door on my first visit, shaking hands and showing me into their sitting room. They chatted freely about their lives. I spent time explaining my research but I was struck by their lack of reference to Ruby’s dementia, recording in my field notes: *Brian talked about Ruby’s condition in very indirect terms and Ruby made no mention of it at all which, in some respects, made it difficult to explain the research* (F 22/8/13). I left the information sheets and, as they were going away, we arranged to meet seven weeks later. On my next visit, Ruby and Brian reported that they did not want to video conversations themselves because: *they did not ‘sit and talk’ and said they were often in different rooms and so talking together may be difficult* (F 10/10/13). They were happy to record me talking to Ruby, or us all talking together, but leaving the camera with them was problematic. Given that they were particularly enthusiastic to do the life story work, we agreed that we would video us all together at a later date. I would visit them for another 15 sessions in total and order the assessments and intervention around their priorities and wishes, thus focussing on the life story work.

4.6.4 Establishing a Baseline – Assessment

After the consent procedure, assessments took place over four visits from October to November 2013 (visits three to six), as summarised in Table 4.6.

**Semi-Structured and Structured Interviews**

In contrast to the other participants in this study, the topic of dementia rarely came up naturally in the conversation. When we met alone Brian informed me that he had instigated the memory assessment. Ruby had, very reluctantly, attended for an appointment with her general practitioner and then the memory clinic where, sitting alongside Brian, she was given the diagnosis of semantic dementia, as Brian describes: “*I think she was a bit stunned. You know, she didn't really think there was anything wrong with her*” (I 20/11/13). Ruby, therefore, had not sought an explanation for her symptoms but had found herself in this conflicting situation. Brian also reported that it was not in Ruby’s nature to discuss her worries with him, if she had any: “*If there is [any worries], she doesn't tell me, she'll not tell me. I've*
never heard Ruby turn around to me and say ‘I’m worried about something’” (I 20/11/13).

Table 4.6 - Summary of visits with Ruby and Brian

<table>
<thead>
<tr>
<th>Session Number</th>
<th>Date</th>
<th>Main activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22/08/13</td>
<td>Getting to know Ruby and Brian and explaining study</td>
</tr>
<tr>
<td>2</td>
<td>10/10/13</td>
<td>Addressing concerns and questions about the study</td>
</tr>
<tr>
<td>3</td>
<td>17/10/13</td>
<td>Explaining and signing consent forms</td>
</tr>
<tr>
<td>4</td>
<td>15/11/13</td>
<td>Initial life story interview together</td>
</tr>
<tr>
<td>5</td>
<td>20/11/13</td>
<td>CAPPCI interview with Brian, all looking through photos</td>
</tr>
<tr>
<td>6</td>
<td>28/11/13</td>
<td>Interview with Ruby, all looking through photos</td>
</tr>
<tr>
<td>7</td>
<td>13/12/13</td>
<td>Piloting potential captions for photographs for life story book</td>
</tr>
<tr>
<td>8</td>
<td>14/01/14</td>
<td>Piloting potential captions, information sheet about condition</td>
</tr>
<tr>
<td>9</td>
<td>28/01/14</td>
<td>Video of conversation &amp; piloting of photographs and captions</td>
</tr>
<tr>
<td>10</td>
<td>06/02/14</td>
<td>Neuropsychological assessment</td>
</tr>
<tr>
<td>11</td>
<td>13/02/14</td>
<td>Sifting through photographs, preparing for discharge</td>
</tr>
<tr>
<td>12</td>
<td>27/02/14</td>
<td>Piloting of new sections and identifying gaps in the books</td>
</tr>
<tr>
<td>13</td>
<td>13/03/14</td>
<td>Discussed using and continuing books, sheet given</td>
</tr>
<tr>
<td>14</td>
<td>20/03/14</td>
<td>Final pilot, sheet – communication in semantic dementia</td>
</tr>
<tr>
<td>15</td>
<td>31/03/14</td>
<td>Review of work to date</td>
</tr>
</tbody>
</table>

At my next visit I saw Ruby on her own and, as my field notes describe, she indicated that she was aware of the diagnosis but showed no wish to talk about it:

She clearly recognised that she had memory problems and said that it’s ‘ok at the moment’, I was struck by the words ‘at the moment’ because this obviously meant to me that she understood that it was a problem that could get worse. She did not really open up, but neither did she seem particularly upset by it (F 28/11/13).

However, at a later session, Ruby did report problems remembering people’s names when out and about (I 13/12/13). It was clear that Brian, in contrast, wanted as much information as he could about the condition and had found looking it up on the internet unhelpful: “It talks about the frontal lobotomy and all the rest of it. It doesn’t actually explain why it’s called, I mean, I know semantic means words, but they don’t seem to explain what it is with the memory” (I 20/11/13).
I asked Brian if he thought Ruby would want any information about her condition, to which he replied: “No, she wouldn’t want to know that, as long as she feels that she’s well” (I 20/11/13). Provision of information about semantic dementia, therefore, was focussed on Brian. Ruby and Brian had not shared the diagnosis with anyone except one of their sons and his wife and did not want to tell even Ruby’s close friends, with Brian indicating a supportive response might not be forthcoming:

*Brenda is a person who would use that knowledge as a hoop to get back at her. She would say something in the pub, well I told you that last week, have you forgotten already. That’s the type of thing she would say to her, and I don’t want that to happen* (I 26/01/14).

Whilst I had thought naively that her friends might be able to offer her support if they understood her diagnosis; the reality was the opposite and a salutary lesson.

Brian completed the DEMQOL-Proxy (Smith et al., 2005) giving a score of 114, reporting that Ruby had a good to very good quality of life, with few worries about symptoms of memory change or functional decline. This score is well above the mean of 92, reported for those with mild dementia in a study by Banerjee et al. (2006). Brian reported very little stress arising from his caring role with a score of 4/13 on the Care-giving Burden Scale (Gerritsen and van der Ende 1994). He reported mild concern that Ruby did not appreciate all that he did for her and some concern with interactional issues, for example, feeling embarrassed over Ruby’s repetitiveness when out with others.

**Interviews about Conversation and Analysis of Video Data**

I will briefly list the challenges with conversation, but will return to the conversation analysis in more detail when considering outcomes. The information here was gathered through interviews using the CAPPCI (Perkins et al., 1997, carried out on 20/11/13 and 28/11/13, see Appendix 13 for full results), observation during visits and analysis of audio data from interviews. A summary of the audio data used to analyse conversation in this case study is also provided in Appendix 13. Ruby’s difficulties with language were fairly mild and she was able easily to hold a conversation, however, there were some changes in her talk, including:
• Mild word finding difficulties, semantic paraphasias and increased use of vague terms and pronouns but no evidence of prolonged struggle to access words.

• Subtle problems in understanding, including missing the point of jokes or requiring Brian to repeat himself.

• Telling particular stories to others that she had told before and a tendency at times to have long turns in her talk due to excessive detail in her stories.

Brian felt they were able to manage these difficulties at home. However, when they were out socially, Ruby’s habit of telling the same stories to people who had heard them before, marked out her conversation as unusual and to those that knew her, as different. Given they had not disclosed her diagnosis, this was problematic.

4.6.5 Formulating and Delivering the Intervention

In formulating the intervention I was conscious that Ruby was being swept along by events not of her choosing and I therefore did not want to impose information on her. She was, however, very happy to talk about her life and so life story work was an intervention that potentially would be both acceptable and enjoyable and focussed directly on Ruby. At this point it was unclear as to how life story work might influence Ruby’s interaction; for example, it was easy to encourage Ruby to talk, in fact talking too much was the issue at times. In contrast, Brian wanted information about the condition and there were therefore three strands to the therapy:

• Life story work focussed on Ruby, with Brian involved.

• Information about the condition for Brian.

• Identifying practical strategies for managing language and memory.

Life Story Work

I began the life story work in session six, 20th November 2013. A big bag of photographs appeared and Ruby, Brian and I spent sessions six to 14 looking through these (alongside other tasks) and exploring Ruby’s memories of past events and what she liked to talk about. We recorded a number of these sessions. I would type captions under photographs I had copied, referring to the audio recording to ensure I labelled items as Ruby described them. I would take draft materials to show
them, to ensure I adequately reflected Ruby’s words, spelt names correctly and the layout was acceptable.

It became clear early on that Ruby’s appearance was very important to them both and being well dressed, attractive and young looking for her age was a crucial part of her identity. There were, for example, stories of Ruby being the first person to wear a mini skirt in the area (I 13/12/13), being taken for her friend’s daughter (I 14/01/14) and other men signalling their attraction to her, even when Brian was present (F 17/10/13, I 15/11/13). Ruby’s love of high heels was legendary in their family and even on the beach, or going for a walk in the mud, Ruby would still wear her heels as she tells me here: “I never had flats, never [laugh] . . . all cobbles and everything. Everybody were looking at me, oh! And I never fell off them or anything” (I 13/02/14). I used a photograph from the internet to illustrate this, alongside one of her in shorts and heels on holiday. I also sourced a picture of racks of high heel shoes and a messy pile of high heels too, as this was how Ruby described her wardrobe. I had wanted to take a photo of her own wardrobe but she was reluctant to do this because she felt it was not tidy enough for a photo. She also liked shoes and handbags to match (I 13/12/13). An extract from her life story book is contained in Figure 4.4, with photographs of Ruby removed for anonymity. Ruby was able to recognise the people in the photographs and aspects of her appearance, even from some time ago but placing the location was often a problem, as I describe in my field notes:

*I was struck that Ruby remembered the coat she had on in one of the photographs, telling me all about where she bought it and what a lovely furry coat it was, yet she had no idea where the photograph was taken* (F 28/11/13).

Brian would attempt to prompt Ruby, but even when given the place name, she remained unsure about the location. Holiday locations were particularly problematic, although Ruby did have a general memory of various holidays. For example, she could not say which cruise picture was which location, even with the name of the ship in the picture but she could describe enjoying cruise holidays, particularly getting dressed up for the ship’s entertainment. Brian, in contrast, could recall all the
It was not that photographs did not trigger any memories but that aspects of the details, particularly locations, appeared to have been lost.

Figure 4.4 - Extracts from Ruby’s life story book (each an individual page)

Therefore, we included photographs of them both on cruises but with general captions such as ‘getting all dressed up – on a cruise’ (Ruby’s picture) and ‘Brian on board ship – these are taken on one of our cruises’ (pictures of Brian). I only
included details, such as place names, if Ruby could recognise clearly the information. We discussed the need to focus on Ruby’s memories, rather than facts like place names. Together, we carefully considered complex family dynamics and how to display these, including information relating to the death of Ruby’s daughter.

By our tenth session on the 6th February 2014, we had too many photographs for one book and consequently I had to make at least two books and find some meaningful way to organise these. I therefore considered the recurring stories that Ruby liked to tell to ensure the materials adequately reflected these and removed any material that was repetitive. I laid out the materials I had gathered and looked through extracts of our transcribed interviews to see how stories naturally linked in Ruby’s conversation, rather than placing photographs in a chronological order (see Figure 4.5). For example, Ruby would often talk about hobbies as a child and then explain why she had to give those up because of illness in the family, before moving on to tell me about her family at that time and her brothers and sisters now. I therefore organised pictures in that order and then moved on to another thread. I used A5 books, with removable pages, placing a picture of ‘glamorous Ruby’ on the front cover. We completed a final pilot of the books in session 14 (20/03/14) looking through to alter any spellings, information not conveyed adequately or pictures requiring re-ordering.

Figure 4.5 - Organising materials (blurred for anonymity)
On the final session, on the 31st March 2014, I gave Ruby her completed books, one with major storylines, another with ‘family events’ (weddings, birthday parties etc.) and a third virtually empty book (only one page completed) so that they could continue the process if they wished. Brian knew how to scan photographs and we discussed that captions could be written neatly underneath rather than typed. We discussed a sheet I had prepared: ‘Using Life Story Books’ (see information sheet one in Appendix 13). As I had learned from Sarah and Doug’s cases, in the future, aspects of the books might not mean as much to Ruby as they did now or events that she wanted including now, such as the fact her daughter had passed away, might be upsetting at a future time. The sheet stressed the dynamic nature of life story work in semantic dementia and that whilst adding to the book was important, it was also appropriate to remove any pages that were not meaningful, did not spark conversation or led to distress. The format of the books allowed for this practice.

Information about the Condition
Brian actively asked for information about semantic dementia because he had been given no advice to understand Ruby’s symptoms. I therefore reviewed websites and advice sheets from a number of sources: including the Frontotemporal Support Group UK, (2013), Association for Frontotemporal Degeneration, USA (2013) and Cerebral Function Unit, UK (2103) along with information generated from other case studies in this project and my assessment of Ruby and Brian’s case, to produce an information sheet entitled ‘Common Questions’ (see information sheet two in Appendix 13), which I discussed with Brian on the 14th January 2014 (visit eight). Ruby, in contrast, was willing to engage in more practical discussions about keeping well and active and we had a number of conversations about this (for example, recorded in F 13/03/14). On reflection, perhaps this was consistent with her longstanding practical approach to life, as well as her current ability to take on board the information on offer.

Identifying Practical Strategies for Managing Language and Memory
One of the most challenging areas to manage was Ruby’s conversation difficulties when out with friends, who were not aware of her diagnosis, including her habit of telling the same stories with extensive details. Brian reported that he would intervene
when necessary to gently move the conversation forward, or provide clarifying information for the listener. In this way the story became told together with more structure to help the listener to follow the point of the story. This, however, was designed to pass Ruby off as someone without dementia and not a strategy that would stand the test of time.

Brian, Ruby and I also discussed how to manage problems with understanding. Ruby was more easily offended these days, and I wondered if this lay, at least in part, in her misunderstanding the talk of others and the situation. For example, whilst humour sometimes diffused a difficult situation, it was also important for Brian to watch for signs of Ruby misunderstanding his intent. We discussed these communication issues in sessions eight (14/01/14) and 14 (20/03/14) and I provided a general sheet summarising this, ‘Conversation and Semantic Dementia: Information for Families’ (see information sheet three in Appendix 13).

4.6.6 Outcomes of Intervention – Reported Outcomes

Reviewing the life story work at our last session (I 31/03/14) Ruby reported that: “it's been smashing, yeah” and Brian quipped: “it's nice looking back, as far as I'm concerned, because I didn't realise how good looking she was!” They would have liked the sessions to continue and could not identify any changes they would make to improve the process indicating that the intervention had been acceptable to them both. Brian, in particular, indicated how important it was after the diagnosis to focus on what was important in life and it had reminded him of all the good times they had together: “If you look back, it's been a good life style . . . but, I mean, the nights out we used to have, it used to be, it was tremendous, we really did” (I 31/03/14) and he added:

I read something in the paper once about the advice someone would give to couples who were on the point of divorcing. The thing was, he said, forget why you're divorcing now and think about why you got married in the first place. So what I'm saying is, not look at the problems which, like, have led to divorce, back to why you wanted to get married in the first place, how you got on and all the rest of it. I thought that was good advice that really, because it
is. And I think the same kind of thing's happening here, from my point of view anyway (I 31/03/14).

In describing the work in this way Brian appeared to indicate that, at an emotional level, remembering the good times together had helped him during this present phase. Ruby’s reactions were more practical and the life story work had led her to retrieve and try on a number of her old clothes from the back of the wardrobe and attic. On my last visit she proudly showed me the handbag from a photograph taken 40 years previously: “I got it out, I put it somewhere and I thought, I'll start to use that now the summer's coming” (I 31/3/14).

4.6.7 Outcomes of Intervention - Conversation

I will now consider how the life story books influenced Ruby’s interaction. To do this I first considered the issues in Ruby’s conversational speech without the life story book, as reported by Brian and evidenced in the recorded conversations with us all present.

Challenges in Everyday Conversation

Using the principles of conversation analysis, I noted recurring features in Ruby’s conversations during audio recordings taken from visits four to six (15/11/13, 20/11/13, 28/11/13) using NVivo 10 to aid this process. I then made a collection of transcripts containing these features, which were subjected to further conversation analysis and discussion during supervision. Firstly, I will present two striking features in Ruby’s talk that were present in our conversations:

1. Holding the conversational floor and topic drift.
2. Recurring topics.

Issue 1 - Holding the Conversational Floor and Topic Drift

Brian reported that Ruby’s habit of talking at length and failing at times to hand over the conversational floor was an area that he found difficult, as he explains:

I said [to Ruby] when you're talking, don't have a long conversation, have a short conversation, I think, you know, she'll find it better. Because sometimes, when she's talking for quite a time, she'll get mixed up (I 20/11/13).
Brian reported that the way he managed this was dependent on the situation. At home he said: “If it was [with] me, I would tell her, you see, don't be going on too long or something like that”. But things were more difficult when they were out together:

If I'm sat at the side of her, I'll try and give her a nudge, but it doesn't always work that. I think if it's not, if she's not making any errors in speaking, I just let her ramble on. But if she made a mistake, I wouldn't interrupt her in front of people, I think I'd try and cover it up by interjecting into her speech  (I 20/11/13).

In my field notes I recorded how animated Ruby became when telling a story and how she acted out the dialogue of speakers using direct reported speech, particularly I noticed: the way she doesn't just tell you about the events but the way she almost acts them out, with great emotion (F 28/11/13). Brian was unable to tell me if this animated style had been a longstanding habit or had arisen since the onset of semantic dementia. The repeated use of enactment with direct reported speech was noted in Doug’s earlier talk (Kindell et al., 2013) and within this study, as well as within Sarah’s stories in case study two. Whilst it might be regarded as positive that Ruby was talking and holding her own in conversation, it was sometimes hard to follow her train of thought within these longer sequences. She also gave additional details that were not essential to the story-line, often obscuring the point she was trying to make and often incrementally drifting away from the topic of the conversation. For the purposes of conversation analysis, I was interested in whether any of us signalled at the time whether such trouble was apparent and there were a number of instances of this, as I will now illustrate in the following extracts:

**Extract 46) - Topic Drift 1 - an argument with a friend (I 15/11/13)**

I had been interviewing them both about their lives and Ruby told me a long story about an argument with a friend. Brian it appears sensed this had drifted away from the focus of my interview and directly refocuses Ruby back to my questions (003 in green):

```
. . . Ruby telling a long story about her friend . . .
001 R I don’t know with her at all
002 J yeah
003 B go on let’s get through these questions then
```
Ruby’s provides an apology “sorry love” (004) and the initial part of my response “it’s alright” (005), illustrates my awareness that this is delicate and attempts to reassure her before I focus back on the topic of the “happiest time in your life…” (005-006).

Extract 47) - Topic drift 2 - moving house (I 15/11/13)

Ruby begins to tell a story about moving from her old two bedroomed house to their current three bedroom house; direct reported speech is presented in bold text. She had wanted another child, a girl, as she already had a son. The point of this story is that they moved but she had a boy in the end, so they could have stayed where they lived. This extract illustrates how, as she moves into talking about the garden of their old house (008), the topic begins to drift into discussion about swings in the garden (012-014):

Brian appears to sense that the topic has drifted with “anyway that’s all in the past” (015 in green). The problem with Ruby’s habit of drifting off the topic is that she
then misses to clearly tell the point at the end of the story. In line 017, I bring her back to the story and this particular point: “so you wanted a little girl…”

There are other examples of this nature where Ruby talks at length. For example, a story about missing the bus one night and having to walk home appears to have additional detail about the bus, the bus stop and step by step details about the location of her house. As the listener to this story, I ask questions to clarify events, e.g. when the story took place, or attempt to summarise important points that seem to have got lost in the detail, e.g. “so you missed the bus home”. The numerous steps in the story are linked with the use of “and” and “and then”. This extract is contained in Appendix 13, labeled extract 48. Ruby, as Brian indicated, was not always aware that the listener was struggling to follow her talk or that the additional detail was not necessary.

**Issue 2 - Recurring Topics**

In addition, Brian had noticed that Ruby had a tendency to tell the same stories, often to people who had heard them before: “you know the story about how I met her and took her to York and she threw her boyfriend out, and that kind. She still tells that to people who know about it. So she'll still repeat that” (I 20/11/13). The video data illustrated this, as evidenced in extracts 49 and 50 below:

**Extract 49) - Recurring topic 1 (I 15/11/13)**

Ruby is telling me about how she met Brian:

<p>| | | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>001 R</td>
<td>I was going out with a lad called Tony and he</td>
<td></td>
</tr>
<tr>
<td>002</td>
<td>said would you like a day out to York</td>
<td></td>
</tr>
<tr>
<td>003 B</td>
<td>I think you’ve had this before</td>
<td></td>
</tr>
<tr>
<td>004 R</td>
<td>Have you heard it before</td>
<td></td>
</tr>
<tr>
<td>005 J</td>
<td>No I’d like to hear it again though</td>
<td></td>
</tr>
</tbody>
</table>

**Extract 50) - Recurring topic 2 (I 28/11/13)**

Ruby is talking about a holiday abroad:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>001 R</td>
<td>it went on for just a couple of days didn’t it</td>
<td></td>
</tr>
<tr>
<td>002 B</td>
<td>I think you’ve told her this before</td>
<td></td>
</tr>
<tr>
<td>003 J</td>
<td>I don’t remember carry on and tell me it’s</td>
<td></td>
</tr>
<tr>
<td>004</td>
<td>alright</td>
<td></td>
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</tbody>
</table>
In both instances Brian notes the repetition. I had heard these stories before in previous sessions, but wishing not to offend I urge Ruby to continue (lines 005 and 003, respectively). As I have indicated, the consequences of this behaviour was dependent on the context, for me it was not a problem, I had the time to listen and wanted to gain a language sample. However, other social situations were different.

**Conversation with the Life Story Book**

The next stage of analysis was to consider the way, or ways, the life story book influenced conversation. I explored the transcripts from our first life story interview *without* the book (I 15/11/13) and a later session *with* the book (I 27/02/13) to compare the conversations and examined my observations recorded in my field notes. I chose the first session (I 15/11/13) because this one was essentially a conversation about their life without the aid of photographs and the second (I 27/02/13) because the book was virtually complete at this stage and we spent a considerable part of the session using the book. I again looked for recurring patterns within the data and considered if those features present in the transcripts without the book, were present in conversations with the book. My aim was not to ascertain which conversations were ‘better,’ rather, to examine whether they were different and, if so, consider how and why the life story book might be influencing interaction. I will first discuss some general issues and then present further detailed analysis.

During sessions with the life story book I had noticed the relative absence of the long sequences of talk from Ruby that were evident in our earlier conversations without the book, as if the presence of the book was making Ruby stop and reflect as I describe in my notes:

> *Ruby for example looks through the books, much like one would with a photo album, often at times in private reflection. This means she is not always making eye contact but looking down at the book. She does look up and make some conversation but it’s not as continuous as when she is talking without the book* (F 27/02/14).

I also noticed the books encouraged more of the humorous side of Ruby’s character. She would roar with laughter when we looked at pictures of her in high heels or her
huge hoop earrings on holiday. In contrast, unstructured conversation often led to less positive topics, often topics of complaint, as this entry from my field notes illustrates:

I have noticed that much of her spontaneous conversation is about problems in her life and the arguments she has had or is having with people, particularly her friend at the moment. The book seems to shift the conversation onto more positive topics about good times in her life or about things that she enjoys and so when looking through the book we see a different Ruby come to life (F 27/02/14).

To explore the data further I examined the first 42 minutes of each interview, to ensure consistent lengths of analysis (the shortest interview being this length) and counted turns at talk for each participant. I also counted the number of utterances containing direct reported speech present in each data set, an assessment carried out in the exploration of direct reported speech in Doug’s earlier talking (Kindell et al., 2013). This analysis revealed that whilst the the long stretches of talk from Ruby appeared to have been reduced in the life story situation, Ruby had slightly more turns at talk with the life story book, illustrating that she was still involved in the conversation, as were Brian and I. In the earlier interview, there were 67 utterances from Ruby containing direct reported speech but when using the life story book this was reduced to 10 utterances. There is also a reduction in the use of direct reported speech by both Brian (22 to 9) and I (13 to 1), in each situation. This data is summarised in Table 4.7.

Table 4.7 - Quantitative aspects of interview and conversation with life story book (LSB) including turns at talk and utterances containing direct reported speech (DRS)

<table>
<thead>
<tr>
<th></th>
<th>Ruby interview</th>
<th>Ruby with LSB</th>
<th>Brian interview</th>
<th>Brian With LSB</th>
<th>Jackie interview</th>
<th>Jackie with LSB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Turns at talk</td>
<td>211</td>
<td>229</td>
<td>205</td>
<td>187</td>
<td>202</td>
<td>171</td>
</tr>
<tr>
<td>Total n° utterances with DRS in</td>
<td>67</td>
<td>10</td>
<td>22</td>
<td>9</td>
<td>13</td>
<td>1</td>
</tr>
</tbody>
</table>
Whilst this analysis is problematic in that it compares two very different tasks, at two different points in time in our relationship, it again, like the observations I gathered through field notes, indicates that the presence of the life story book may change the dynamics of interaction, perhaps arising from the structure of the task. In particular the reduction in direct reported speech from us all, but especially Ruby, may indicate that whilst a number of topics are covered in the life story books, this is at the expense of extended stories where features such as direct reported speech are more likely to be displayed.

The life story structure certainly allowed for others to introduce new topics into the conversation therefore moving the conversation forwards. For example, viewing video data of us all engaged in life story work, Brian can be seen to move Ruby off from a topic about the hairdressers that has become extended and rather circular, by physically pointing back to the photographs present, saying “these.” This prompts Ruby to conclude the topic, put her glasses back on and resume looking at the photographs. A long conversation about an argument with Ruby’s friend in the pub is curtailed by me introducing pictures of her love for dancing as a child (see Appendix 13 for extract 51). Thus, Brian and I are observed to use the life story materials to gently end an extended topic and this seems to offer an indirect strategy to do this, which saves face for Ruby. This strategy allowed for a more even distribution of the conversation and encouraged collaboration in the conversation. In this way, the life story book provided a ‘conversational anchor’; a way to focus the conversation and a strategy for others to use to reduce Ruby’s habit of incrementally drifting from the topic at hand. In addition, in contrast to conversation, the life story book structure gently legitimised repetition of the stories she liked to tell.

However, it could also be argued that the life story book gave Ruby less opportunity to use her skills with extended storytelling or that not allowing her the time to speak, as she may wish, was not person centred. This issue was complex and contextualised because such extended turns at talk were causing Brian some difficulty and, even at home, it was not always possible for Brian to sit and listen for as long as Ruby required. The conversation also had a feeling of imbalance and, whilst talk was forthcoming, there was also a sense of disconnection at times. This presents as an everyday interactional dilemma, balancing the needs of both parties and this issue is
likely to be relevant for those individuals with semantic dementia who, like Ruby, tend to hold the conversational floor in their talk. Perhaps one way through this may be to consider not that one activity is superior to the other, but that the life story structure gives interaction something different for Ruby and Brian, an alternative choice from everyday conversation. There is a shift onto different topics with a reduction in stories of complaint. Importantly, the life story work re-established an opportunity for ‘sharing’ in communication, a vital factor influencing relationships and clearly, from their reports, they both enjoyed the life story work.

4.6.9 Reflections on the Intervention
The analysis from this case study indicates that it should not be assumed that life story work naturally leads to improved interaction in all cases and further, the complexities of interaction mean that making judgements about improvements in talk are not simple; for example, the gain in one conversational feature may lead to loss in another. Life story work offers a structure that is different from casual conversation and whilst, in some instances this may be helpful, there is also the possibility that the structure might be constraining. From a clinical perspective, I found Ruby and Brian’s case interesting, as I have seen other people with semantic dementia who also present as ‘very talkative’ and whilst practice based advice is available to encourage talking in people with dementia, the complex issue of how to manage conversations in those who are potentially over-talkative is less apparent. The life story work also displayed potential to identify broader goals in terms of activities and care planning for the future that involved the person with semantic dementia without necessarily discussing the condition. This was helpful as Ruby was reluctant, or unable, to talk about the impact of dementia on her life.

4.6.8 Closing Contact and Future Needs
I stressed on my last visit the need to see the on-going nature of life story work and there were indications that Ruby and Brian might continue with this activity, for example, talking about sorting through all their old photographs and Brian reported he would take his camera out again (I 31/03/14). I was, therefore, pleased in August 2014 to receive an email from Brian telling me about some photographs he had taken of them on a trip together.
The life story work also enabled us to talk about activities to keep well, without specifically discussing the dementia, a topic Ruby was reluctant, or unable, to talk about. We considered activities Ruby particularly valued (getting dressed up and going to the pub for a dance) or Brian needed (his quiet drink on a Friday night) and activities that they had stopped doing (going for drives). We identified practical steps that might be needed to support these in the face of increasing need. I hoped that Ruby and Brian would find the support they needed to continue with those things important to them both. Ruby remained under review by the memory clinic with appointments planned for every nine months at the hospital and they were aware of where, and how, to access additional help should they need it.

4.7 Case Study 5 – Ken and Brenda

4.7.1 Introduction
In my final case study I present a gentleman, Ken, who had recently been diagnosed with very early semantic dementia and his wife, Brenda. As this case study unfolds it will become clear that whilst Ken was in need of support following his diagnosis, neither interaction-focussed therapy nor life story work (in its original form) were appropriate. I will show how I needed to tailor my intervention to offer Ken the support he and his wife needed following diagnosis. In this case, Ken engaged in an adapted form of life story work himself aiming to focus attention on important aspects of his own identity and, simultaneously, reduce his focus on the symptoms of his condition. At this time of transition, the aim was to use life story work as a foundation for adapting, coping and living well with semantic dementia.

4.7.2 Background
Ken, age 66, had received a diagnosis of early semantic dementia at a specialist memory clinic. The neurologist from this centre referred him into the study reporting that Ken was very worried about the decline in his communication skills. Ken was a retired university lecturer in art history, having taken early retirement some ten years previously on health grounds. He lived with his wife Brenda, a retired solicitor, and their daughter. They had another daughter and one son, who were both married with their own children and lived some distance away. Ken and Brenda had met at
university and had married soon after this, settling in the area they now resided, to be close to work opportunities.

4.7.3 Our Initial Encounters

On my first visit on the 23\textsuperscript{rd} August 2013 I was struck by the beauty of Ken and Brenda’s house, which, although old, had retained many original features both inside and out. As Ken showed me from the hall into the lounge, I could see a number of unusual ornaments, furniture and paintings on display. It would be later that I would find out more about these objects, but this first encounter was entirely taken up with exploring Ken’s worries about his diagnosis. In my field notes on this day I wrote: *Ken struck me as a man seeking an explanation for his symptoms* (F 23/8/13). Ken was able to tell me in great detail about the many doctors he had seen including different general practitioners, a hospital doctor, psychiatrists from working and older age mental health services, before finally a neurologist. He was not sure if he had been diagnosed correctly with semantic dementia, wondering instead if he had Alzheimer’s disease. He appeared very anxious throughout this first visit and I found myself on the back foot, directly answering his questions about the condition and trying to reassure him about it, as this field note entry illustrates:

*Ken said that the Dr at [specialist centre] had said she had hardly ever seen anyone with his condition. I think Ken has got ‘the wrong end of the stick’ with this one, and so I explained to him that the team are experts in semantic dementia and see lots of people with this condition. However, they may not have seen so many people so early in the course of their illness* (F 23/08/13).

Ken explained various problems he encountered with language and memory, but I could see little evidence of these difficulties in conversation recording in my field notes: *I observed very little evidence of language disorder, e.g. no particularly prominent word finding problems and he understood everything I was telling him and in conversation* (F 23/08/13). It would be on my second visit (11/09/13) that I would meet Brenda and it became apparent that she did not share Ken’s worries about his symptoms as I recorded in my field notes:

*It became clear quite quickly that they both had differences of opinion about Ken’s symptoms. Brenda was clearly saying that she wondered if Ken even...*
had a dementia because his problems were so mild. She said he was a ‘glass half empty’ character and Ken agreed with this. She therefore felt that he was reading more into the problems than there was actually there (F 11/09/13).

Ken and Brenda were happy to take part in the research, but like Ruby and Brian in the previous case study they did not want to video themselves alone reasoning that this would make their conversation awkward and contrived. We, therefore, agreed to video later and with us all together.

4.7.4 Establishing a Baseline – Assessment

Between October 2013 and January 2014 (visits three to seven) interviews were carried out with Ken and Brenda separately and with them together. Life story work began alongside this in session five (19th November 2013) with further advice and therapy in later sessions. Table 4.8 provides a summary of these encounters.

Table 4.8 - Summary of visits with Ken and Brenda

<table>
<thead>
<tr>
<th>Session number</th>
<th>Date</th>
<th>Main activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>23/8/14</td>
<td>First visit with Ken to discuss research, Brenda not present</td>
</tr>
<tr>
<td>2</td>
<td>11/9/13</td>
<td>Meeting with Ken and Brenda together</td>
</tr>
<tr>
<td>3</td>
<td>24/10/13</td>
<td>Signed consent forms, initial identification of helpful strategies</td>
</tr>
<tr>
<td>4</td>
<td>5/11/13</td>
<td>Ken on his own, neuropsychological assessment and interview</td>
</tr>
<tr>
<td>5</td>
<td>19/11/13</td>
<td>Ken on his own, interviewed, discussion of life story work</td>
</tr>
<tr>
<td>6</td>
<td>16/12/13</td>
<td>Seen together and session with video, identified lack of activity and potential strategies to address this</td>
</tr>
<tr>
<td>7</td>
<td>8/01/14</td>
<td>Interview alone with Brenda</td>
</tr>
<tr>
<td>8</td>
<td>24/1/14</td>
<td>Seen together, identified need for further information about the condition, reinforced ‘keeping well’ message</td>
</tr>
<tr>
<td>9</td>
<td>14/2/14</td>
<td>Seen together, verbal and written information given about semantic dementia and summary of discussions</td>
</tr>
<tr>
<td>10</td>
<td>17/03/14</td>
<td>Review of goals</td>
</tr>
</tbody>
</table>

Semi-Structured and Structured Interviews

Ken completed the DEMQOL (Smith et al., 2005) on the 5th November 2013 giving a score of 82/112, with Ken indicating that, whilst he enjoyed life and his overall quality of life was good, he had significant worries about his memory. This score is below the mean of 92 for those with mild dementia reported in a study by Banerjee
et al. (2006) and at a level identified for potential interventions to address quality of life by memory clinic staff (Banerjee et al., 2007).

It became clear that due to the early nature of Ken’s semantic dementia, some of the study’s structured carer interview schedules were not appropriate or meaningful. For example, Brenda did not regard herself as ‘a carer’; she was Ken’s wife. She was not even sure herself if she believed Ken had dementia, so she felt she had no stress arising from her caring role when the Care-giving Burden Scale (Gerritsen and van der Ende 1994) was administered (visit seven, 8/1/14), with no issues identified on any items. To assist in formulating the intervention, a number of key areas were identified over the course of the first seven encounters and these are now described.

**Conflicting Opinions** - The difference in how Ken and Brenda viewed the semantic dementia was a recurring theme in our encounters. Ken stressed his symptoms and progression, whilst Brenda questioned the validity of Ken’s assessment of his situation, or tried to reassure her husband that things were not as bleak as he described. I recorded in my field notes:

> Brenda said she tried to “minimise things” because she did not want them to get out of proportion. Ken said he is worried that he is rapidly deteriorating and so he sees things very much as being a problem (F 24/10/14).

It seemed that Brenda’s attempts to reassure Ken did not help and during the sessions this sometimes led to disagreements. When we met alone, Brenda relayed that this issue often caused arguments between them: “we’ve had countless arguments . . . I think it is mild, like you, if I said that he had it mildly he would blow up and get really cross” (I 8/1/14).

**Personality and World View** - We identified in our sessions that Ken’s outlook on life, before his diagnosis, was rather pessimistic. Ken felt that whilst parts of his life had turned out well, overall he had a tendency for bad luck:

> And Brenda won’t agree with me on this one but, you know, I tend to think that I have, I believe in such a thing as luck and I don't have good luck. And that's why she thinks I'm pessimistic (I 5/11/13).
In her interview (I 08/01/14) Brenda confirmed that this belief about ‘bad luck’ had been a long standing view. Ken’s views on life in general often coloured his responses to my questions, e.g. when asked if he was enjoying life Ken volunteered:

*I sometimes think life is wonderful, great, but other times I think, there’s not a lot to live for. I don’t like the way politics are going, I don’t like the way the country is going, I don’t like the way the world is going, I don’t like lots of things* (I 19/11/13).

Ken and Brenda both spoke about the difficulty in sifting through what might be long-standing traits in Ken’s personality, such as being ‘pedantic’ and ‘inflexible’ (their words), and what might be a change due to the onset of semantic dementia. By visits five and six (19/11/13 and 16/12/13) we were able to openly discuss if perceived changes to Ken’s personality was due to the dementia or had arisen from natural changes as he had become older and adjusted to retirement.

**Sharing the Diagnosis** - During the assessment period Ken and Brenda revealed that they had not shared Ken’s diagnosis with any other members of the family, including the daughter they lived with, or any of their friends. I was surprised by this, particularly given Ken’s anxiety about his diagnosis. Ken reported that he did not want to worry his children:

*I’ve not actually spoken to my children and I don’t know whether I should, I don’t know whether I should say, you know, I’ve been diagnosed with this and da da da da da da, I don’t know [Jackie - Why wouldn’t you?] I don’t want to worry them and I don’t want them to be dismissive by saying things, like, oh, don’t be daft, you know, so I don’t know whether to just let it just drag on and just let it drift in* (I 19/11/13).

I enquired if Ken thought his children had noticed any changes in him, he replied:

*They might not have picked up on memory, but I’m sure they’ve picked up on my behaviour and I tend not to get involved in conversations with them as much as I used to and I perhaps don’t, I don’t give the impression that I’m a loving caring father and grandfather. I suspect I don’t do that like I did a few years ago* (I 19/11/13).
Ken’s Description of his Symptoms - Ken was able to provide extensive information about his difficulties and here I provide some examples to illustrate these. Overall, Ken reported that he was less interested in conversation and that it was not so easy to take part these days: “I can’t really participate in it much at all, [like] the others; I’m not flowing as I used to be able to flow” (19/11/13). Specifically, Ken described difficulties with making a connection in his mind between a word used by another person, or that he read and its associated meaning, telling me:

Now, if that word came up, ‘koala’, I’d think I know that word, and it’s only now that I know that it’s an animal . . . koala, you know, I could have been thinking is that an Italian dish, you know what I mean? (I 19/11/13).

Ken described that parts of knowledge was “shrinking” (I 5/11/13). Interestingly, he also said it was sometimes hard to know if he had ever known these things before: “sometimes I can remember and I think I did know that, but now, I don’t know it, sometimes I can’t remember whether I ever did know (I 19/11/13). This did not just relate to knowledge of words, Ken described feeling that he was losing some of the memories of his life experiences. He had, for example, tried to remember his time at work at the university but, despite much effort, this was problematic: “the other day, I was thinking about how did I teach, what did I teach the students, what did I do? I can’t remember. And it’s not like centuries ago (I 5/11/13).

Strategies - Ken and Brenda had made some adaptations to the problems in conversation. Ken often spoke about the need for ‘triggers’ to help him make the connection between a word and the corresponding meaning. However, whilst he was thinking, he was sometimes left behind in the conversation, as he illustrates here:

I can't remember places and people's names. . . . if someone mentions something and I'm trying to put pieces together, trying to find triggers, trying to do this, that and the other, then I've just lost track of the conversation because I can't concentrate on listening because it's moved on (I 5/11/13).

With Brenda, however, it was easier to stop and request extra information but this was more difficult when he was out socially with friends (I 19/11/13).
Analysis of Video Data
Together, Ken, Brenda and I video recorded one of our sessions (sessions six, 16/12/13). I therefore hoped by this point that some of their anxieties about the video process had been reduced. The recording began by us talking about Ken’s difficulties before we moved to a life story interview, talking about their lives together prior to the dementia. I have observed the video on two occasions looking for potential problems with language, memory or conversation skills but have found no issues of concern. In my clinical opinion the data looks, in this instance very much like a normal conversation. This is not to say that Ken was not experiencing changes in his talking. The neuropsychology (see Appendix 4) only shows very mild changes and it is likely that this leads only to occasional problems in conversation, perhaps where there are competing and higher level demands for language. In this relaxed and informal situation such problems had not been elicited.

4.7.5 Formulating and Delivering the Intervention
Although Ken described many problems with his communication and memory, few were observable in our sessions or displayed on the video. This meant that we could not explore Ken’s difficulties through interaction-focussed therapy as envisaged in the protocol. Clearly, however, Ken worried greatly about his difficulties and therefore intervention was required to support him and address the issues he raised. From my first visit I had been concerned about Ken’s psychological reaction to his symptoms and that this might impede his adaption to his condition further over time. There were, therefore, different aspects to the intervention:

- Providing information and counselling about the condition.
- Identifying practical strategies for managing language and memory.
- Life story work.

Providing Information and Counselling about the Condition
Whilst Ken was keen to understand semantic dementia, I was concerned that much of the written information available might not be helpful to him. Firstly, it was carer focussed rather than aimed at the person with semantic dementia. For example, I searched semantic dementia on the internet whilst preparing information for him (15/01/14) but could see that most of the stories of personal experience were written
by family carers, rather than the person with dementia and, likewise, information from health and voluntary agencies was targeted at carers. Secondly, I had become concerned that Ken’s outlook meant that information could make him focus on negative symptoms, or dwell over symptoms he currently did not have. I had become aware that when Ken mentioned an issue I had become cautious as to whether to focus on this as a potential symptom of semantic dementia, or not. Ken had, for example, mentioned difficulties with coordination in his fingers and “muscle wasting” (his words), as this entry from my field notes shows:

*I am beginning to wonder if Ken is testing me at times. Particularly when he mentioned the ‘muscle wasting,’ I wondered if he had read about the [established] connection between motor neurone disease and frontotemporal dementia and if he was testing me to see if I was going to react to this in any way, i.e. to confirm his suspicions. I am finding that I am increasingly becoming guarded as to what to tell Ken (F 19/11/14).*

On this occasion I avoided asking any questions about this directly and chose to ask about coordination indirectly on my next visit. At this stage he had no symptoms indicating motor neurone disease, or any other muscle wasting condition, and this was confirmed by the neurologist.

I therefore chose to explain semantic dementia to Ken and Brenda verbally and follow up with a short accessible leaflet in session nine (14/02/14) that I had written myself outlining the condition, in general terms, but using language appropriate for someone in the early stages of semantic dementia (see Appendix 14 for the sheet entitled Semantic Dementia: Common Questions). I used the questions they had asked me over our earlier visits to structure the information and also took some of the themes we had identified in our discussions, particularly the notion of ‘making connections’ between words and their meaning as the most salient symptom. I used information from a number of websites to gain inspiration including: The Frontotemporal Dementia Support Group, UK (2014), Cerebral Function Unit, Manchester UK, (2014), Alzheimer’s Society UK (2014), University of California, San Francisco, Memory and Ageing Centre, (2014) and the Frontotemporal Dementia Toolkit (Eastern Cognitive Disorders Clinic, Australia, 2014). The Frontotemporal Dementia Toolkit presents as the most person centred of these
websites/documents, however, overall, there was generally little evidence to guide self-directed management strategies for individuals living with semantic dementia. I included some brief information about the need to keep active in terms of exercise, social activities and hobbies, as health promotion strategies have been advocated as important for physical and mental health across the dementias (Alzheimer’s Society, 2014).

In reality, the process of information and counselling had begun at our first session and was threaded through each session, until our last. It was unethical for me, as an experienced clinician, not to address Ken’s questions about his condition as they arose, or to clarify any misconceptions he had had about his condition, especially those that were causing him distress. For example, on my first visit (23/08/13) I reassured Ken that the neurologist he had seen was skilled in the diagnosis of semantic dementia, as he was questioning their experience with this condition. During session four (5/11/13), we discussed that whilst researching his condition on the internet, he had read that younger people with dementia deteriorate more quickly. I explained that whilst some people deteriorated quickly, others had the reverse pattern. In session six (16/12/13), I advised Ken to visit his general practitioner to discuss his mood, as I was concerned that he might be depressed. This he did and an antidepressant was prescribed.

Despite the neurologist’s assertion he was in the early stages of semantic dementia, Ken repeatedly questioned this, saying his scan had shown severe atrophy of his brain. In session eight (24/01/14) I drew a diagram of the brain in an attempt to show Ken the report indicated a very small part of the brain showed atrophy, not the whole brain. I agreed to write to the neurologist and asked them at the next appointment to explain this result again. In session nine (14/02/14) we discussed whether looking up the condition on the internet was helpful, given that there was a lack of information on early stage semantic dementia and the exercise only served to make him depressed. In my field notes from this day, I noted Brenda referring to this task as “pointless”. We both urged him to consider reducing this and to ask the neurology clinic staff any questions he had about his condition.
These discussions drew on my knowledge as an experienced clinician using both my understanding of semantic dementia and dementia in general. Whilst some of Ken’s questions were specific to semantic dementia, other anxieties overlapped those of people with all types of dementia following a diagnosis, for example, issues of disclosure of the diagnosis to others. In session five (19/11/13) Ken and I first talked about the fact he had not yet told his children about his diagnosis, as noted earlier. We returned to this theme again at our next session (14/12/13) when, with Brenda present, we discussed the pros and cons of disclosure. I raised, for example, that they both might need support about the condition or whether their children were wondering about any changes in Ken. I noted in field notes from that date that I was concerned that if Ken did not tell them about his condition, then Brenda might discuss the issues with his children without him present, potentially setting up a cycle of communication about Ken, not with Ken.

The process of the research had opened up discussions between Ken and Brenda and a clear acknowledgement of their different perspectives on the severity of Ken’s problems. During my interview with Brenda on her own (8/01/14) we discussed this at length and how the reassurance she was trying to provide was not working for Ken and, in many respects, proving counterproductive. At this session she reflected that she was now trying to avoid getting into those discussions whenever possible.

**Identifying Practical Strategies for Managing Language and Memory**

In terms of managing Ken’s symptoms, we had identified in session three (24/10/13) with both Ken and Brenda present, that adding in extra information was often needed for Ken to make the connection between a spoken or written word and it’s corresponding meaning and this we called ‘enriching the message’. Thus, when talking, if Ken failed to understand then adding in extra personal detail would help him make the connection, e.g. a restaurant name might be triggered by saying when they went, what they ate there and any memorable issues about the place rather than the name of the town or street where it was, because of Ken’s particular problems with place names. With written reminders Ken was advised to write down additional information, for example, not just the name and telephone number of a person, e.g. ‘Peter + number’, but ‘Peter, the fence painter + number’. We returned to this on a number of occasions, including in session nine (14/02/14) when I provided a written
sheet summarising the areas we had discussed in therapy (see Appendix 14 for sheet entitled Summary Sheet – Areas Discussed).

Ken had identified that, when cycling, he could not always associate a place name on a road sign with the actual place and this, on the odd occasion, had meant he had got lost. He did have a mobile telephone with satellite navigation but this had broken and he had returned to a very old handset. Brenda had been teasing him for being “too tight” to buy a new mobile telephone for some time and we had a humorous discussion in session three (24/10/13) about why a new one would be useful. There was a serious side to this, as I noted in my field notes from this date. I was concerned that as Ken deteriorated, associating place names on road signs could become more problematic and getting used to using satellite navigation on his mobile telephone now, when he only needed it occasionally, might help develop a strategy he would increasingly require.

**Life Story Work**

At this point, Ken did not need a life story product to support his talking because his difficulties were so mild. However, we had identified that he had developed a habit of testing himself on whether he could remember the name of the artist and title of each of his paintings around the house. If he could not remember Ken would become frustrated and irritated with himself. Whilst this behaviour indicated Ken’s desire to maintain this knowledge, I was concerned that this strategy could also damage his self-esteem. Given the importance of this knowledge in Ken’s life, it was this area we targeted for life story work. In session five (19/11/13), we discussed ways to carry out this work. Initially, I expected I would need to take photographs of his paintings and work with him to produce the text. However, Ken already had on his computer a picture of each painting with the value for insurance purposes. We, therefore, agreed to ‘enrich’ this with further details from a personal perspective, e.g. what he liked about the painting, when they bought it (as this were often purchased on trips away) and any other information to tell a story about it. Ken would then periodically read through this information to refresh his memory. Ken was very keen to do this and he quickly completed this work.
There was also a practical aspect to the life story work. Ken had identified in our early sessions that he was not as active as he used to be and he wanted to do more, perhaps aiming to be as active as Brenda who attended a variety of social groups, as this quote illustrates: “I’ve never felt the need to do anything like that, because I’ve always been busy and occupied and never felt it, but now I’m beginning to think, maybe I should do these things” (I 19/11/13).

Ken described enjoying “craftsmanship” and “artistic work” such as making furniture or renovating the house (I 19/11/13), but that he had not engaged in such activities of late. He had considered re-decorating the house but felt the decision making within this activity was onerous, e.g. deciding on colours, styles, furniture, carpets etc. Ken also talked about a desire to take up painting. As shared earlier, Ken had been a lecturer in art history and had sporadically painted the odd picture over the years. In session six (16/12/13), we discussed pursuing this activity and outlined practically how Ken could begin, for example, deciding upon what equipment to buy. I considered that this activity might stand Ken in good stead during the early stages of his dementia. Semantic dementia does not involve visuo-spatial skills and so we could expect Ken to maintain the visual and perceptual skills required in painting for some time and there are anecdotal reports of individuals with this condition maintaining, or even taking up painting with some success. Potentially, therefore, I felt this hobby could build on Ken’s strengths. I also considered that spending his time pursuing a positive activity may also distract him from worrying about, and researching, his condition.

4.7.6 Outcomes of Intervention

By session eight (24/01/14) Ken had completed the ‘enriched self-generated life story work’ on his computer about his paintings. He had enjoyed doing this, finding the task relatively easy. Ken kindly printed off some pages of his work and agreed for me to show them within this dissertation. Figure 4.6 provides an example of some of Ken’s work. This image is deliberately blurred to maintain confidentiality. Each entry was completed in this way with a picture of the painting, alongside a description, e.g. who painted it, what is significant about the artist or the painting.
and then a personal connection, e.g. when it was bought, why or an aspect that Ken liked about it.

Ken reported that he had stopped testing himself on the names of paintings and artists and instead read these pages and he found this a more helpful strategy as this entry from my field notes indicates:

Toward the end of the session Ken said that he was feeling a bit less pessimistic about things. He said he had found it very helpful to do the art life story stuff himself and he was reading through this on a regular basis and this was helping him, he thought, keep the names in his mind (F 24/1/14).

This work could be expanded in the future, if Ken wished, ultimately using this information for a much broader self-generated life story resource or be used in a portable life story resource containing paintings, much like the one I had completed with Peter in case study one. Interestingly, there was some overlap between this kind of life story work and word re-training tasks in semantic dementia (e.g. Savage et al., 2014) in that both identified target vocabulary items to maintain. However, within

Figure 4.6 - Ken’s life story work – an example
the life story work here, the vocabulary items were embedded within a personalised context, generated by Ken, not the researcher.

On our last session, which I audio recorded, Ken reported that he had started to worry about forgetting the names of neighbours and sometimes lay in bed at night testing himself on these. Brenda felt this was not helpful: “It’s destructive is that. I’ve told you that before” (I 17/3/14). We agreed to use the same strategy with neighbours’ names, i.e. to write these on his computer with an ‘enriched self-generated’ description and read this rather than test himself and Ken felt this was a good idea.

Ken reported that he had taken up painting, finally getting round to buying the equipment he needed and they were both pleased with this. He was experimenting with different techniques and pleased with the results so far, reporting:

*The first one was a landscape that I found on the internet. It wasn’t a painting, it was a photograph. So I interpreted that. The next one was when we went to Seville and I took loads of these spectacular views, and I made a painting of one of those views which I think is pretty good. Then the next one I’ve done is sort of a composite thing where it’s partly photography of our house but I put it in a much more pleasant surroundings . . . so the next one I want to do, something a bit more impressionist or even expressionist, and a bit looser* (I 17/3/14).

In terms of activity, the only area that Ken identified as potentially an issue was that he wondered if he was getting enough exercise and so at our last session (I 17/03/14) Ken resolved to make some enquiries at the swimming pool and gym. Ken had purchased a new mobile telephone with a range of features that he was now using including a ‘reminders’ section and satellite navigation.

Overall, Ken said he felt a little better about things and that his mood had improved. Brenda felt that Ken was “less panicky” as outlined here: “I feel that you have been less, oh, ‘what’s that’, ‘where’s that’, ‘where’s that place’, ‘what’s that word’, less panicky, I think generally you are calmer,” and to this Ken agreed (I 17/3/14).
There appeared to be significantly less tension between Ken and Brenda about his condition; I recorded in my field notes: *They both report that he has been ‘obsessing’ (Brenda’s words) less about the diagnosis and he says he is looking [his condition] up less on the computer* (F 17/03/14). At this final session, Ken also referred to his potential deterioration in different terms. For example, earlier in session three (24/10/2013), Ken was complaining of a rapid deterioration, but now described his symptoms as: “I just can’t remember, so it definitely is an issue and definitely is deteriorating. But it might not be very rapid deterioration. I don’t know” (I 17/03/14). Ken had told his son about the diagnosis and was pleased he had done this, reporting his reaction had not been as dismissive as he had feared. At this last session we discussed focusing on keeping active and engaged in positive activities and he reported: “Yes. I think I have accepted that that is the only thing that can help remedy my feelings, because I recognise that there isn’t anything that medically can be done to stall it or clear it” (I 17/03/14).

I spent some time alone with Ken and we completed the DEMQOL together (I 17/03/14). This indicated Ken was worrying less about his symptoms than when I first met him, although he did still worry about the future. There had been an improvement on his overall score, now at 96/112 (compared with 82/112 at baseline) and above the mean of 92 for those with mild dementia in the study by Banerjee et al. (2006). I felt this was a fair reflection of the change that I had seen in him and Ken reported that he had no particular worries presently. Ken was keen to know if he had helped me in any way and I reassured him that I had learnt a great deal of important information about living with the early stages of semantic dementia.

### 4.7.7 Reflections on the Intervention

Ken’s case illustrates how a person with early semantic dementia may actively engage in life story work themselves, with only structure and guidance provided by the practitioner-researcher. Therefore, in this case study the majority of the work on the life story was carried out between sessions by Ken, not by me. Life story also offered a structure to reflect on broader issues of activity in life. Whilst Ken had undertaken many of these tasks himself, e.g. taking up painting, buying a new telephone etc., I considered that the therapy sessions had helped set goals for him.
and encouraged him to move away from talking and procrastinating about such matters (as Brenda often referred to it) and engage in concrete actions towards these goals.

**4.7.8 Closing Contact and Future Needs**

Whilst I was pleased with Ken’s progress, I was concerned that he might need further support in the future to maintain the changes we had made and address any new issues that arose. Locally, he did not meet the criteria for involvement of the memory clinic, because he already had a diagnosis and there was no (Alzheimer’s) medication to monitor. I therefore discussed further support with him and Brenda and we agreed to refer him to the local speech and language therapy service and ask them to contact him in the autumn of 2014 to review his progress. I hoped this would provide them with some continuity of support. I spoke to Ken on the telephone in July 2015 and he reported he was generally doing well and was now on his 13th painting.

**4.8 Summary**

This chapter has presented the five case studies and the interventions delivered in each case. Participants presented at various stages of semantic dementia from the earliest to the later stages of the condition. A range of issues with conversation were uncovered in each situation and, following a detailed understanding of each case, intervention was tailored to individual need. This led to life story work being delivered in different ways, with different formats, in the five case studies with a range of outcomes. Interaction-focussed therapy was carried out in case study one with changes in post-therapy conversations at home documented. In two cases interaction-focussed therapy was not indicated and for another two cases, video recording conversation at home proved problematic. The next chapter draws together these findings by exploring the data further across case studies.
CHAPTER 5

Cross-Case Analysis

5.1 Introduction
This chapter presents the cross-case analysis of the data. The chapter begins by describing the recurring features evident in everyday interaction. The analysis then turns to an important area, the theme of adaptation. This explores how the person with semantic dementia, the carer, and together as a couple, they adapted to changes in interaction in their lives. The interventions and their outcomes, delivered across the five cases, are explored. Lastly, developed from the data in this study, an exploratory model to underpin life story work in semantic dementia is presented. The process of cross-case analysis, including triangulation of data was described in Chapter 3 and the table derived from this analysis has been placed in Appendix 15.

5.2 Everyday Interaction in Semantic Dementia
In terms of everyday interaction, whilst there were common themes in the issues presented, there were also many differences between the case studies. This might be expected given the different stages of semantic dementia present amongst participants, therefore leading to different levels of language difficulty. However, the data also illustrated differences in how family carers managed interactional needs in the home situation and how the person with semantic dementia adapted to the changes in their own interaction. I will first describe two areas with respect to the conversation data: i) language difficulties present in conversation and ii) issues with conversation skills. In the section following this I will outline issues of adaptation.

5.2.1 Language Difficulties Present in Conversation
As expected, difficulties with language were present within the conversation samples, with the individuals in the first four case studies all displaying evidence of a language disorder in terms of both expression and reception of language. In terms of word finding, however, regular and overt struggle to find words was only present
for Peter, with other participants generally showing fluent speech with increased use of pronouns, proforms and empty substitutions rather than overt struggle.

In terms of understanding, whilst questioning the meaning of words, e.g. “monkey?” was evident on neuropsychological testing, this was less apparent in conversation. Sarah was the only participant that displayed this behaviour with any regularity. Ken reported that he experienced difficulty associating the names of people and places he heard or read, but this was not evident within the interaction data studied. The other participants all displayed varying degrees of difficulty with understanding, but such problems appeared more subtle or were signified in other ways such as through the lack of an expected response in the conversation, or the absence of a required physical response, rather than by repeating the word back. For example, I have illustrated that Peter often appeared to understand what was said to him but that at certain times when he was required to demonstrate a response, such as laugh at the correct point in a story, this was not always forthcoming. In Doug’s case relatively good nonverbal skills meant that he listened intently, often laughed at points in the conversation and would appear to respond appropriately with responses such as “absolutely”. However, the video recordings that Karina made at home indicated significant challenges with understanding, as evidenced by the need to physically guide Doug to do what was required, when shaving or putting on his slippers.

5.2.2 Challenges with Conversation

In terms of broader conversation skills a number of challenges were demonstrated in the data with issues surrounding topic being a recurring feature. I will now explore three aspects of this in the data:

1. A lack of conversation.
2. Reduced repertoire of topics of conversation.
3. Repetitive questions.

1. A Lack of Conversation

All the family carers in the first four case studies reported in their interviews that the person they cared for did not initiate conversation as much as they used to, with the carers of Peter, Sarah and Doug reporting that a lack of conversation was a particular
problem at home. The video data, from these first three case studies, confirmed the carers’ reports. When viewing the data, I noted that the participants were often far less talkative at home, alone with their spouse, than I had observed during my visits.

In case study four, the picture was a little different with Brian reporting that Ruby initiated less conversation, however, when she did start a topic, at times she talked at length and failed to hand over the conversational floor. This latter behaviour was evident in Ruby’s audio and video data and recorded in field notes. In Doug’s earlier data set, a similar pattern was also reported within the interviews, with Karina reporting that Doug did not talk enough at home, while the speech and language therapist who was interviewed, reported that on her visits it could be hard to encourage Doug to relinquish the conversational floor (Kindell, 2011). Ken reported about his own talk that he was not engaging in conversation like he used to:

\[I\] tend not to get involved in conversations with [the family] as much as I used to and I perhaps don’t, I don’t give the impression that I’m a loving caring father and grandfather, I suspect I don’t do that like I did a few years ago (I 19/11/13).

2. Reduced Repertoire of Topics of Conversation

It was evident within the data that three participants had a reduced repertoire of topics of conversation, often talking about the same topics or telling the same stories: Peter, Sarah and Ruby. In addition, this had been a problem for Doug in the past, whereas now Karina reported that Doug’s speech was too difficult to follow to understand the topic. Whilst this was a mild problem for Ruby and Brian to manage, for Peter and Joanna, and Sarah and Reg, this was more striking within both the interview and the video data. Analysis indicated that context influenced carers’ reactions to recurring topics, with four of the carers reporting that it depended where they were and with whom the person was talking, as to whether this was problematic or not.

This study has also explored the perspective of the person with semantic dementia with respect to these recurring topics and illustrated that these individuals often derived a great deal of pleasure and stimulation from engaging in such topics, using verbal and embodied behaviours. Sarah, for example, was observed in the video data
to say “I can remember this . . .” and become very animated when telling the story of her first job, acting out the dialogue and using a range of body movements to display the scene and her work as a machinist (V 23/04/13). She therefore appeared to recognise this conversation as one that she could still remember and conversation analysis showed that it was a conversation where she displayed many skills.

3. Repetitive Questions
The area that I found most surprising when reviewing the video data was the significant amounts of repetitive questions asked by Peter and Sarah. This was often the same, or a very similar question, and most often tied to the routine of the day or meeting basic needs. In my clinical practice I had been aware of this, but it was only on viewing video of the couples alone together, did I fully appreciate how challenging this must be in everyday life. The respective carers, Joanna and Reg, both admitted this was a very difficult area and that at times their patience was tested to the limits.

5.3 Adaptation to Conversation Changes
Adaptation was a prominent theme in the cross-case analysis, with evidence of both positive adaptations as well as strategies that appeared maladaptive in some cases. Adaptation related to particular strategies to manage conversation changes as well as broader approaches to life as individuals and as couples. The process of adaptation was continuous as progressive changes occurred within interaction and daily life and therefore potential barriers to adaptation arose along the way, requiring a degree of flexibility in approach. I will first discuss adaptation in the person with semantic dementia, then move to consider how family carers, in turn, adapted to these changing needs and finally consider how issues of adaptation played out within relationships.

5.3.1 Adaptation – The Person with Semantic Dementia
Some of the ways the person had adapted to changes in communication appeared to be deliberate strategies either arising from the advice of others or from conscious thought. Some of these strategies appeared helpful but others presented as potentially problematic. Peter, for example, wrote a daily journal following advice from the
local speech and language therapist and hoped that this would stimulate his language skills and so, initially, this was a deliberate strategy. Ken had developed a habit of testing his own knowledge of painters and paintings. As I have described, whilst this was an attempt to retain this knowledge, the behaviour also caused frustration and could be damaging to his mood. It could, therefore, be argued that this behaviour was a conscious strategy but, also, that it had the potential to be maladaptive in terms of maintaining Ken’s self-esteem. Brenda also held this view, when Ken revealed he was also testing himself on the names of his neighbours whilst lying in bed at night, she told him sharply: “It’s destructive is that. I’ve told you that before” (I 17/3/14).

Other behaviours that appeared to be attempts to adapt to changes in conversation were less deliberate and more spontaneous; these conversation practices involved attempts by individuals to use their remaining skills as best they could within interaction. For example, Peter had developed a habit of showing items to support his telling, illustrated on my first visit when he was waiting for me with his tennis score card in this hand and told me, using these items, about his love of the game (F 24/08/12). Peter’s habit of repeatedly asking questions about the routine, e.g. “what are we doing today?” after a lull in the conversation, is perhaps another example of a naturally occurring adaptive strategy, i.e. an attempt to use the skills and understanding still available to him to strike up a conversation following a period of silence.

Doug, in the earlier data set, was shown to use a recurring practice of enactment in conversation, whereby he would use direct reported speech, pitch, loudness, facial expression and body movements to act out, or depict, scenes within the conversation. Doug’s behaviour was presented as a form of adaptation, i.e. an ability to use the resources he still had at his disposal to accomplish meaningful interaction, despite his difficulties with communication (Kindell et al., 2013). In the later data set presented in this thesis, Doug continued to use direct reported speech, appearing to act out conversations using the same resources. However, the decline in his language skills made it harder to follow his speech. In the data gathered from both Sarah and Ruby’s conversation there is also use of direct reported speech, with this appearing particularly striking in Ruby’s case. Like Doug, Ruby effectively used a number of resources to convey the events and the mood of the scene she was telling, including
verbal means within the direct reported speech and other resources such as body movements, facial expression, pitch and loudness. It was difficult to ascertain in Ruby’s case if this arose from a longstanding habit of telling such animated stories about her life or a change due to the dementia. Longitudinal data collection with Ruby would have been interesting to uncover if such features persisted with time, or were used differently in the future, to track such potential issues of adaptation. There were other behaviours of a more performative nature, which appeared to be adaptations within interaction by the person with semantic dementia. These I will explore later, following discussion of the intervention.

5.3.2 Adaptation – Family Carers
I now turn to examine how family carers adapted to the person with semantic dementia’s communication needs. Signs of positive adaptations were present in all carers, however, there were also areas where carers appeared to struggle or were using practices that appeared unhelpful, or maladaptive, particularly from the perspective of the person with semantic dementia. There were a number of areas in relation to this and I will now describe each of these.

Comprehension: A range of difficulties with understanding were reported and observed in the data, from very mild misunderstandings or problems linking a word with a concept, through to considerable difficulty understanding even simple instructions. Strategies observed and suggested by family carers to manage these included:

- Helping the person associate a place name by using a personally related description, e.g. if unable to remember the name of a restaurant describe the last visit to that place, or additional specific sensory information, e.g. explaining the supermarket with reference to the smell of chocolate from the factory next door.
- Directly showing the person what was being discussed.
- Using Google images to show pictures and photographs.
- Using leaflets, photographs or other pictures to support talk.
- Being aware that joking in some instances could lead to misunderstanding.
It was clear that one set of strategies was not suitable for all participants. For example, Ken, due to the early nature of his condition, generally required extra verbal information to connect ideas, words and concepts; a plan we called ‘enriching the message’. However, Peter could be easily confused if verbal and nonverbal information appeared contradictory, whilst Doug needed physical guidance to understand everyday self-care tasks.

**Test Questions and Repair:** Another area relevant for adaptation was the use of test questions, i.e. asking questions when the answer was already known, and associated repair strategies. It was evident within this data that test questions could be viewed as both problematic and a useful resource for conversation, depending on the context. The test questions posed for Peter by Joanna tended to lead to difficulty due to his word finding difficulties and, therefore, lack of ability to provide the answer to the test question. In addition, because Joanna tried to prompt, cue and encourage Peter to think of particular words for himself, long sequences of talk then ensued in search of a target word or piece of information, which was already known to Joanna. As a result reducing the use of test questions was one of the targets in therapy, along with Joanna providing the word, if Peter was struggling and the word was known.

However, there were instances where, in contrast, test questions were helpful. For example, Reg was observed to use test questions to deliberately elicit a particular topic or story from Sarah, at times leading to an extended response. Karina also used test questions with Doug, but would quickly provide the answer when trouble in the conversation ensued and he was unable to respond. In these instances Reg and Karina appear to be using test questions as a device to invite Sarah and Doug into the conversation and they provide the required information quickly if the person with dementia was unable to provide it.

**Memory and Tag Questions:** The data provides some interesting insights into the management of repetitive questions and memory in semantic dementia. In this study Sarah and Doug exhibit significant problems with memory. Their spouses, Reg and Karina, are noted to use a recurring practice of giving the information, followed by a tag question, e.g. Reg: “so you didn’t have a good night’s sleep last night, did ya?” (V 9/02/13), Karina: “because Paul Brown came to see us, didn’t he?” (V 16/08/13).
This strategy appears to function as a gentle and embedded way to circumvent the memory failure, in that the information is given in a statement, avoiding placing the person with semantic dementia in a position to recall information or mark the memory problem in the conversation. The tag question then functions as a device to draw the individual with semantic dementia into the conversation with a variety of appropriate responses. By using this formulation of ‘state and draw in’ Reg and Karina appear to design their turns in a way that enables some conversation about recent events but does not require Sarah or Doug to recall the event themselves. There is also some evidence of Joanna using such formulations at times in the post therapy data, for example, when she asks Peter a test question about where the family have gone on holiday, rather than pursue Peter to say the particular word as she may have done before therapy, she uses a statement followed by a tag question: “they’re in Wales, aren’t they” (V 18/08/13).

**Recurring Topics:** Returning to the issue of recurring topics and stories, there is evidence in this data indicating differences in how carers treated such topics. Joanna, for example, was often observed not to pursue such topics when initiated by Peter. Reg, in contrast, was actively seen to encourage such topics, even initiating them himself. Ruby also had a habit of telling the same stories but Brian’s concern was not about this behaviour at home, but how this marked Ruby’s conversation out as different in social situations; this was problematic because they did not want others to know that Ruby had dementia. Brian, therefore, talked about how he would step in during such occurrences in the conversation.

Carers in the first four case studies reported that their reaction to various changes in interaction and behaviour depended on the context, with particular vigilance required when out in public and in some instances this involved thinking about whether or not to go to social gatherings or certain places, depending on the tolerance of others.

**5.3.3 Adaptation – Broader Issues for Relationships**

This study explored narratives of those living with semantic dementia and their spouses as well as direct observation of natural conversations at home. Data were, therefore, gathered from descriptions of relationship issues as well as providing a
window into the in-the-moment performance of relationships. In all cases carers were interviewed separately, as well as with the person with dementia, to allow for a full and open expression of feelings. People with semantic dementia were also offered interviews on their own and two chose this option, Ruby and Ken; with Peter, Sarah and Doug requiring or requesting for the carer to be present because of communication difficulties. The data indicate different recurring storylines in how couples appeared to face semantic dementia in terms of interaction. Sarah and Reg, and Doug and Karina, both appeared to be working together in the face of semantic dementia as evidenced by both their reports and interaction styles.

Sarah and Reg, for example, presented as a couple with a united front, both agreeing that semantic dementia was difficult but life had to go on and they talked openly about Sarah’s dementia. They both spoke of acceptance and their comments reflected a similar approach: “this dementia thing . . . I just have to try and get on with it” (Sarah, I 26/2/13) and “you play the hand that you’ve been dealt in life” (Reg, I 26/02/13). Reg also displayed a clear recognition that the dementia was the problem, not Sarah: “I don’t see the point in arguing with somebody who can’t help what they’re doing” (Reg, I 26/02/13). The conversation data also echoed this stance, essentially Reg did not argue and they ‘got on with it’, generally very well, within their interactions.

It was not possible to interview Doug about his views. However, despite the advanced stage of Doug’s condition and challenges in their past relationship, Karina often spoke about her attempts to consider Doug’s well-being and this was reflected within her constant attempts to keep him connected to the social world both in the past data set (Kindell et al., 2014b) and this current project. For example, when asked if she ever felt resentful, she reported: “I think I probably did at the beginning and now that’s out of the way. I think it’s acceptance and the fact that this is a human being that you almost feel responsible for” (I 05/09/13). Karina openly stated her aim was to stimulate interaction, rather than conversation and analysis revealed that, in spite of significant communication difficulties, positive interactions focussing on well-being were highly evident.
Ken and Brenda, and Peter and Joanna, however, showed evidence of a conflicting approach with each partner in the couple exhibiting a different perspective from the other, this presenting as a potential barrier to adaptation. For example, Ken and Brenda had a difference of opinion even on whether Ken really had dementia. When talking together, Ken would emphasise how challenging his symptoms were and Brenda would attempt to reassure him. However, this only served to persuade Ken that Brenda was minimising his difficulties and therefore not supporting him, leading to further disagreements.

Peter and Joanna also presented with different viewpoints, with Peter rationalising that things could be worse than “my memory problem” (as he referred to it) often telling the story of a relative who died at a young age, however it was clear observing Joanna’s reaction to Peter’s story that she did not share Peter’s way of looking at the situation at all (F 24/08/12). It was exhausting watching Joanna’s attempts to stimulate Peter to find words on the video and perhaps curious as to why she had not naturally given up with this approach, particularly given the overwhelming sense of grief and loss she was experiencing. However, it could be argued that this strategy was part of her broader reluctance to accept semantic dementia into their lives and was actually tied to her sense of grief and her attempts to preserve Peter as he was prior to his dementia, thus holding on to his skills. Her comment that it was “like giving up on him” if she gave him the word more readily (F 8/03/13), providing further support for this. As such, stories of loss were recurring features in Joanna’s interviews. In contrast, Peter did not share this sense of loss.

Lastly, Ruby and Brian’s case presented particular challenges because Ruby’s reluctance, for whatever reason, to talk about her condition, left Brian facing semantic dementia on his own. Their reluctance to tell others about Ruby’s diagnosis meant that Brian was further isolated and I was concerned about how they might manage in the future. Whilst I have no evidence of Ruby’s interactions with others beyond Brian, her interactions with me illustrated the challenges Brian faced in attempting to hide her dementia. Whilst Ruby and Brian were in agreement not to tell their friends, within interaction Ruby was less able to spot the signs that she might be failing to present a competent façade. As a result the work and stress to
achieve the concealment largely fell to Brian and there was a sense of isolation for him within this.

5.3.4 Summary – Adaptation

In summary there is evidence of adaptation to changing needs in interaction for the person with semantic dementia and the family carer. In addition, within each couple, individuals were attempting to adapt as best they could in their given situation. It was clear that for some individuals and couples the strategies they used to help them cope and interact worked well for them at an individual and relationship level. However, for others the situation was more difficult. This was evidenced by maladaptive strategies within interaction. In addition, conflicting views were present about their situation and in how each person coped with semantic dementia. The services offered locally to couples varied significantly, with a lack of practical provision and information about the condition presenting as another potential barrier to adaptation in some cases.

5.4 Interventions: Interaction-Focussed Therapy

I will now consider the interventions explored in this study, starting first with interaction-focussed therapy. Case study one, Peter and Joanna, illustrated that interaction-focussed therapy could be carried out with a couple living with semantic dementia to identify challenging conversation behaviours and make changes in management, i.e. facilitate more appropriate adaptation within interaction. This case study showed that changes in management could be measured post-therapy within conversations recorded at home. In this case, there was a reduction in those conversation behaviours targeted in therapy, i.e. pedagogic behaviour in facilitating known responses and target words, and explicit mention of errors and repetition, along with an associated reduction in overt signs of distress and ill-being within interaction in the person with semantic dementia.

In this case study I was able to draw on my clinical experience in dementia care and deliver the intervention within a sensitive psychosocial framework. This was important as both Peter and Joanna were finding life with semantic dementia increasingly difficult and showing them video illustrating this struggle could
potentially have made the situation worse. Joanna, in particular, felt she was not a natural carer and had a very low estimation of her own competence and there was a danger of reinforcing this, rather than facilitating strategies to help her cope. Joanna, like many of the carers I see in clinical practice engaging in such behaviours, believed she was helping to maintain Peter’s skills. The narrative interview data allowed for a deeper understanding of this practice and to take account of the deep sense of loss that Joanna was feeling.

Interaction-focussed therapy for Peter and Joanna, therefore, focussed on the observable behaviours in conversation, but placed these within a broader psychological and practical frame. For example, ‘accepting and adapting’ was discussed early on within therapy with respect to emotional changes, practical changes and changes within conversation. Our sessions were as much counselling sessions as advice sessions, particularly when addressing emotional issues. However, whilst Joanna readily spoke about the distress she was experiencing, Peter’s views about his own feelings were less evident within interviews, where he often expressed his worry about Joanna. The video data, therefore, had an important function in allowing us to have a window into Peter’s world, to directly explore the emotional impact the challenges with communication were having on him within the interaction.

The case study also highlighted that whilst semantic dementia presents with a language disorder, as the condition progresses changes in behaviour, cognition and relationships leads to a range of challenges in everyday life that are different to those seen in aphasia after stroke. I was particularly concerned about the levels of stress Joanna was experiencing and the lack of a care package meant she had no time for herself. This provides a different landscape for intervention and it was difficult for me, as a practitioner, to deliver interaction-focussed therapy in isolation without attention to this broader context.

5.5 Intervention: Life Story Work

Life story work was delivered in all five case studies, but tailored to individual needs. A variety of different formats were produced including:
Consideration was given to the stimuli that the individual may be most likely to respond to, the context of the family and the situations they would use the resource within to deliver the most appropriate format for the person concerned. The data demonstrated that particular cognitive features impacted on the format of life story work. For example, issues of associative agnosia made photographs challenging for Sarah and Ruby as they were sometimes unable to recognise the people or places in the photographs. Peter, in contrast, had good recognition of photographs but struggled to access words himself to display this recognition. The ability of individuals to use the written word alongside photographs was variable. For instance, Ruby would automatically read captions under photographs with no difficulty whilst Sarah required her conversational partner to draw her attention to the written material. Peter could only make use of the written word when labels were placed directly on the photograph. Sarah, in particular, showed significant dyslexia and this had to be considered when using the written word in her life story DVD.

Issues of memory were also important and for people with more advanced semantic dementia, some memories from the past were hard to stimulate with verbal, visual or sensory cues of any kind and appeared lost, whilst others were recalled more vividly, giving a patchy display of memory change. For example, whilst Sarah could tell an elaborate story about getting her first job, she could say nothing about how she and Reg first met. Moreover, when Reg told this story she showed no recognition of these events at all, despite the striking and humorous nature of the encounter. In addition, for Peter, Ruby and Ken, recent memories were as important as longer term memories within the life story work. For Sarah and particularly for Doug, who were more advanced in their semantic dementia, their cognitive difficulties meant that prompting past memories to use in current conversation had its limitations and that finding creative ways to foster in-the-moment interactions was more productive. In
Sarah’s case this was through music and in Doug’s case, through particular practices that focussed on nonverbal interactional skills.

Considering where, and with whom, participants would use the life story resource, was an important aspect for assessment and effective intervention. For example, for Sarah’s family, singing at home and karaoke at parties was familiar to them and so a music DVD to watch and sing along with was appropriate. For other families in this study, this resource might have been less acceptable within the culture of their family and therefore less likely to be successful. Joanna found Peter’s behaviour of showing his diary repeatedly to visitors difficult given the mistakes it contained. Yet, she was very happy for him to show them his life story books and actively encouraged this. I had been aware for Peter that the presentation of the resource was important and so I was pleased this was happening. Therefore, consideration needed to be given to who would use the life story resource and in what way(s). Four of the participants with semantic dementia in the study directly used the life story resource, with varying degrees of support. Doug’s resource, in contrast, was not for him to use, the aim was for others to use the information contained within it, to improve interaction and knowledge of him as a person.

Whilst the initial study design had focussed on conversation at home, it was clear that interaction in other contexts could be influenced by the life story work. The portability of Peter’s pocket resource meant he could use it in a variety of other settings. In addition, Peter’s already established habit of showing materials and objects to support his telling meant that he adapted well to using this resource.

5.5.1 The Goals and Outcomes of Life Story Work

The life story work was tailored to individual need. There were, therefore, a range of outcomes and the data confirmed that the formulation developed by Kindell et al. (2014) could be used to map these points of connection:

- Interactional connections
- Emotional connections
- Practical care connections
- Building new connections.
In addition, the data from this study indicated there was also a fifth theme:

- Future connections.

I will now discuss each of these points of connection in turn.

**Interactional Connections:** In this study I have demonstrated that the life story resources supported a variety of interactional connections by providing increased opportunities and support for interaction. Peter’s book provided him with a range of topics he did not make reference to spontaneously, a structure to support his word finding and a focus where he became centre stage in the intervention. Sarah’s DVD was shown to facilitate a variety of verbal and embodied connections with her family. Doug’s sheet ‘Making Connections’ focussed on specific ways to connect with Doug, particularly based on his nonverbal interactional skills. Ruby’s resource provided more focussed conversation that was easier for others to follow. In this study, therefore, a variety of behaviours were encouraged including embodied behaviours as well as verbal communication and this contributed to supporting a sense of self and individual identity. Where possible, outcomes examining interaction were directly explored, i.e. examining in-the-moment participation in interaction whilst using the life story resource. Conversation analysis appears promising to explore this and photographs taken during life story activities were also used to examine, and convey, aspects of engagement and embodied behaviours.

**Emotional Connections:** The life story work also fostered emotional connections between family members and the person with semantic dementia or strengthened the person with dementia’s connection with their own identity and this impacted on well-being. This latter aspect was particularly evident in Ken’s case because whilst he identified challenges in conversation, these difficulties were mild and did not require the support of a life story resource. The self-generated enriched life story work, in contrast, helped him connect with his own identity and make changes in coping at a psychological level, i.e. targeting issues of mental health and adjustment to his condition, thus focussing on his interests and how to keep well and active following his diagnosis. Peter was reported to look through his life story book spontaneously himself and he enjoyed doing this, in this way keeping in touch with
his own identity. Topics in the book for Peter were chosen because they were important for him in terms of interaction but, also, illustrated unique aspects of his identity, including his contribution to the household through the jobs he carried out.

The video and audio data illustrated the couples connecting at an emotional level; Peter and Joanna sat closest and displayed most affection when engaged in the life story work. The emotional connections between Sarah and her family were highly evident in the video data, with Sarah telling her daughter she loved her and reaching out and taking Reg’s hand each time with the Cilla Black line ‘my arms reach out to you with love’. This illustrated an embodied emotional connection between them. As I have discussed, whilst Ruby could engage in stories about her life, in open conversation such stories often veered towards complaint stories. The life story work, in contrast, contained a range of topics that encouraged different kinds of stories and different kinds of emotions: those of pride, humour, love (and sadness) that facilitated different aspects of Ruby’s character, identity and well-being. Brian indicated that following the diagnosis of semantic dementia the process had helped him think about Ruby, why they had married and all the good times together, therefore, helping him through this stage.

The life story work, whilst enjoyable, also presented some emotional challenges for family carers. Sarah’s daughter reported that seeing her mother engaged in song was both happy and sad as it reminded her of how she used to be and this she missed. Joanna reported that the process made her think a lot about the past and it was hard to know if this made her miss how Peter had been in the past even more. Lastly, the work also raised emotional connections for me, both in terms of my own emotions and connecting with the participants in the study. For example, Ruby’s daughter had passed away in similar circumstances and in the same year as a close relative of my own and when this topic occurred I was reminded of my own experience and sense of loss.

The outcomes in terms of emotional connections within the data were descriptive or observational, for example, emotional connections were evident in the carers’ narratives and present as signs of emotional connections in the video data.
Building New Connections: This theme was evident in the life story work for Peter and Doug. For Peter his portable life story book helped him build connections with staff and other service users at the various day centres he attended and when he was admitted for respite care. For Doug, his admission to long term care meant that the life story work was now aimed at helping the staff to build a relationship with him. Whilst his previous life story book helped the staff to understand the life Doug had lived, his sheet ‘Making Connections’ presented ways to connect with him in the here and now. As I have discussed, I did not have data to evaluate the life story work in other settings; however, Joanna and Karina both reported that the life story work had been helpful to build new connections for Peter and Doug.

Practical Care Connections: For some individuals the life story work had impacted on important practical aspects relevant to care. For example, Karina reported that the care home was playing Doug’s music on a regular basis and Joanna reported that the day care centres had found the portable book helpful to get to know the activities that interested Peter, such as encouraging him to play the guitar. The life story work also had capacity to help the person with semantic dementia make practical changes in their life, in terms of self-management. For example, Ruby and Ken, both with earlier semantic dementia, took stock of their lives and their interests as part of the life story work and conversations about keeping well with semantic dementia. For Ruby this presented as a way to talk practically about keeping active, without necessarily talking about the diagnosis, e.g. keeping up certain activities and identifying other enjoyable activities she was doing less of late. For Ken, on the other hand, the life story work was part of direct conversations about the condition and a focus on activities to keep him engaged. This study did not directly examine effects on care practices but reports from carers and the person with semantic dementia indicated that the life story work had an impact on this level and in Ken’s case the work directly led to practical changes with him taking up a new hobby.

Future Connections: There were elements of the life story work carried out within the present, but with a consideration of future goals and issues. Ken produced his resource on the computer, to read himself, however, there was potential for this material to be used as a starting point in the future in a portable book or life story book format. Ruby and Brian, for example, reported that they wanted to continue to
add photographs to Ruby’s book in the future leading to on-going life story work. In addition, the study demonstrated that past resources may have current limitations. Sarah and Doug, for example, had well made life story books that had been helpful in the earlier stages but were shown to have limited benefit now in encouraging interaction. For this reason Ruby and Brian were given information about the future use of their life story book in order to maintain this as a dynamic resource. Whilst we had talked about adding to it, I also outlined, sensitively, that if certain pages no longer held interest, or were upsetting, then these could be removed. The format of the book with pages that could be added and taken away made this a more flexible resource than, for example, Sarah’s book which had been printed and bound and so could not be altered. The data presented in this study, therefore, illustrates that life story resources used to facilitate interaction, need to be dynamic resources that are adapted along with the needs of the person with semantic dementia and consideration of future use and adaptations could be built into current work.

5.6 Performance and Music

Issues of performance and love of music recurred in the cross-case analysis, in particular when life story work was considered. For four participants music brought significant pleasure to their lives; three having a long standing interest in listening to music or playing an instrument: Peter, Sarah and Ruby; with one participant, Doug, presenting with a newly acquired interest in this area.

There were a number of behaviours in the data that had a performative dimension. For example, Doug’s behaviour of acting out scenes in his conversation, within the earlier and present data sets had elements that could be considered as performance. Additionally, in this data Doug’s acting out an upper class accent again bears the hallmark of performance, with skilled ability to manipulate phonetic aspects of talk to depict this characterisation. Effective use of such resources, including direct reported speech, can also be seen in Ruby and Sarah’s stories and their combined use effectively depicts, not just what happened or was said, but also important emotional elements of the story they are enacting. Lastly, the analysis of Sarah’s singing when engaged in the life story work, demonstrates recurring aspects of performance,
including embellishments and over-singing and embodied aspects of performance in her body movements and facial expression.

The effects on the audience are also apparent. This is particularly evident in Sarah’s singing data where her family and I observed her abilities, commenting on her beautiful voice and clapping and laughing at her playful manner. Sarah clearly enjoyed this feedback and this, in turn, encouraged her to perform. When Sarah and her family watched the DVD, now as the audience, this gave an opportunity to relive the moment and even perform again together, setting in process a cycle of performance. Sarah, very importantly, was able to display her skill within the performance but also appreciate this skill as an audience member when watching the DVD and this had important consequences for her sense of self. Sarah was delighted at being “on the telly!” as she described this and it was evident to everyone, including Sarah, that she was the best singer in the family. Doug’s upper class accent is seen to impress Karina and me and we talk with curiosity about how good Doug is at this skill. Lastly, as a listener, I have to admit I was sometimes uncomfortable with the high level of emotion conveyed by Ruby in her stories, particularly those that displayed elements of complaint.

5.7 Summary - Intervention

Cross-case examination of the data illustrates that detailed assessment and understanding of each couple was important in order to tailor intervention to their needs. This began with establishing a baseline for intervention through detailed assessment. This involved understanding how each individual and each couple were adapting to changes in interaction and placing this in the context of broader adaptation to life with semantic dementia. The interventions delivered in this study aimed to focus on activities and participation in interaction and enhance on-going adaption to interaction in semantic dementia. Interaction-focussed therapy was carried out in case study one, with successful outcomes. Life story work was carried out with all couples. Whilst the aim was primarily to engage the person with dementia within interaction, outcomes extended beyond this into aspects of emotion, building new relationships outside the home and practical care planning. Work delivered in the present could also impact on activities, or support, in the future.
The study demonstrated that different formats were relevant for different needs and different situations and an important part of assessment was to assess cognitive, psychological and social aspects in order to tailor intervention most effectively. Interestingly, individualised advice around interaction occurred in all cases, often alongside the life story work, as if the life story work formed the foundation, and exploration about interaction in general was built from there. The use of conversation analysis to examine the life story work further strengthened this approach. In this way the life story work focussed on the finer details of interaction both within the life story work itself and also within discussions about interaction in daily life. This indicated that aspects of the two interventions could be incorporated into a common intervention framework, which I now present.

5.8 Interaction-Focussed Life Story Work - An Exploratory Model

Drawing these analytical points and approaches together, Figure 5.1 presents an exploratory model to underpin ‘interaction-focussed life story work’ in semantic dementia, that is, life story practice, with a central aim to enhance strategies for interaction in everyday life.

Aims of Interaction-Focussed Life Story Work:

• To build and sustain connections to the person with semantic dementia, their family carer(s) and others within the context(s) in which they live and socialise.
• To deliver individualised and flexible assessment and intervention in order to identify ways to make and sustain such connections and enhance well-being.
• To enable the person with semantic dementia to take control of their biography and to make maximum functional gain out of residual interactional abilities.
• To facilitate family members to take account of biography past and present, and current interactional needs to foster appropriate adaptation within interaction.
• To make anticipatory goals - to be aware of and plan now, for future strategies to sustain connections.
Figure 5.1 An exploratory model for interaction-focussed life story work

Current Situation and Needs: It is important to explore who the person with semantic dementia regularly communicates with and the interactional skills and challenges arising in these situations. This involves ‘creating partnerships in communication’ (Kindell et al., 2015) involving the person with semantic dementia, their family carers and other significant individuals in their lives.

Potential Future Situation and Needs: This involves considering how the person with semantic dementia’s needs might change and taking account of this within plans for therapy. An example of this could be to consider the potential next steps and future partnerships in the supportive care plan, e.g. enhanced self-management and attention to activity; a support worker or personal assistant; peer support; day care; respite; and long term care.

Life Story: Understanding the Person and their Context: Intervention requires an approach that actively aims to understand the person and their context in terms of their past and present life story, both individually and within their family unit. This
Involves listening carefully to the person with semantic dementia and their family to uncover the areas that mean most to them at this point in time. In semantic dementia this involves exploration of current and past biography and awareness that both contribute to identity.

**Identifying Signs of Well-Being and Ill-Being in Interaction:** It is important to identify those aspects of interaction that foster well-being, those aspects that present with challenges leading to signs of ill-being and examine if those around the person with semantic dementia are aware of these signs. This involves observing the person interacting with others, preferably using video or audio recording for detailed analysis. A focus on information transfer alone should be avoided and consideration of abilities with interaction should be examined alongside transaction. Therefore, abilities with language should be considered alongside paralinguistic features such as pitch and loudness of voice and embodied features such as body movement, pointing and facial expression evident within the sequential development of interaction.

**Life Story Strategies and Products to Support Well-Being in Interaction:** Intervention aims to identify appropriate strategies and products to support well-being within interaction, which takes account of the above areas. Products to support interaction need to take account of the person’s language and broader cognitive needs, the contexts in which they will be used now and, if possible, in the future and the emotional needs of those involved in life story work. Creativity in format is required to meet the person’s needs and this involves considering aspects of conversation but also activities and interests that currently enhance interaction, including creative pursuits such as art and music. Attention should be paid not just to the details of the life story, i.e. the factual information, but also to the performance of narrative. Creative ways may be required to support skills with performance.

**Strategies for Interaction in Everyday Life:** This involves drawing on the areas described and, as in interaction-focussed therapy (Lock et al., 2001): raising participants’ awareness of interaction in general (including issues of transaction and interaction), raising participant’s awareness of their own patterns in interaction currently and identifying strategies to enhance adaptation within interaction, using information drawn from life story work.
Intervention is individualised to the context and requires the partners in intervention to outline their particular goals at this current time and consider ways to revisit and explore these goals during, and after, intervention. It is important to reflect on the potential points of connection within the life story work in order to clarify goals and outcomes, including: interactional connections; emotional connections; building new connections; practical care connections; and future connections.

5.9 Summary

This chapter has highlighted the everyday challenges with conversation described in interviews and directly observed within conversations in this study. An important meta theme within the data has been how the person with semantic dementia and their family carer adapts to these changes, as individuals and together as a couple. As the data from Sarah, Reg and Harriet illustrates this also extends to family adaptation. Analysis indicates that couples present with different patterns of adaptation. This is likely to be a dynamic process, occurring throughout the course of semantic dementia, with changes in need bringing various challenges in adaptation along the way. Intervention can potentially impact on the process of adaptation, as I have illustrated in the chapter with respect to interaction-focussed therapy and life story work. A potential model for further research and practice to underpin interaction-focussed life story work in semantic dementia has been presented, bringing together elements of both interaction-focussed therapy and life story work. An important aspect to this approach is adapting to the needs of the individual and their context and examining the focus and goals of life story work.
CHAPTER 6

Discussion and Conclusions

6.1 Introduction
This final chapter begins with an overview of the study’s contribution to knowledge, followed by detailed discussion of how this relates to the current literature and the implications arising from this study. This will include exploring the study’s findings with respect to everyday interaction in semantic dementia and issues of adaptation to changing needs in conversation for the person concerned and their family. The innovative aspects to the interventions delivered will then be discussed and the potential for intervention to enhance adaptation to life with semantic dementia. The study uncovered important findings with respect to issues of performance within interaction and these are presented with their implications for the representation of semantic dementia. Music was a significant source of pleasure for those living with semantic dementia in this study and this was used therapeutically to enhance interaction. This is discussed along with the methodological innovation used here to explore in-the-moment effects of a music life story DVD with one family. The limitations within the study will be examined and, finally, this thesis will conclude with an overview of the study’s contribution to knowledge for research, practice, policy and education in semantic dementia.

6.2 Contribution to Knowledge
This study worked with five people living with semantic dementia and their family carers aiming to study interaction at home using a combination of conversation analysis and biographical interviewing, followed by exploring potential interventions to support interaction. As far as I am aware, this is the first study to systematically explore everyday conversation in a group of individuals with semantic dementia and their family carers. Building on an earlier case study (Kindell et al., 2013; Kindell et al., 2014b) this thesis used direct evidence taken from conversations within the home setting. This is in contrast to the current literature, where test data, observation in clinical settings or carer reports are the basis for the study of communication in
semantic dementia (Gorno-Tempini et al., 2011; Hodges and Patterson, 2007; Kertesz et al., 2010; Sajjadi et al., 2012). This study makes an original contribution to knowledge by demonstrating the range of skills and, also, significant challenges within the area of conversation for people living with semantic dementia. Importantly, the potential of family carers in adapting to the needs of the person with semantic dementia was shown, including use of specific conversation practices to scaffold interactional abilities which, in turn, contributed to well-being. Adaptation to changing interaction skills was also demonstrated by the person with semantic dementia. By using a novel methodology that mixed analysis of everyday conversation using conversation analysis with biographical interviewing, the study was also able to triangulate issues of adaptation in conversation and relationships, uncovering important knowledge for practice not explored before in semantic dementia.

Until this study neither interaction-focussed therapy nor life story work have been explored as interventions in semantic dementia. Moreover, whilst interaction-focussed therapy has been suggested for dementia care, the approach has yet to be systematically evaluated in any type of dementia and, in my experience, is currently not a commonly delivered intervention in clinical practice in dementia care. As identified in Chapter 1, although life story work is increasingly popular in dementia, the research literature suffers from a lack of critical reflection and research (McKeown et al., 2006; Moos and Björn, 2006). In addition, whilst it is commonly reported that life story work encourages interaction, few studies systematically examine this claim (see Spilkin and Bethlehem, 2003, for an exception to this). This study set out to examine and combine each of these novel approaches in a clinically orientated research study. The study contributes to knowledge by demonstrating that interaction-focussed therapy can be used in semantic dementia to make direct and measurable changes in conversation. However, further work is required in order to explore and adapt this intervention for the needs of this client group. Life story work was delivered in all case studies and was shown to impact on various points of connection; importantly, tailoring the intervention to the needs of each person with semantic dementia and their family carer(s) was crucial. Creativity in practice and research design has also allowed for the exploration of issues of performance in both everyday life and intervention. The study makes an original contribution by taking
the information generated from these case studies to present an exploratory model for ‘interaction-focussed life story work’ that can be used in practice and further research to enable people with semantic dementia and their family carers to be supported in on-going adaptation to interactional changes in semantic dementia. In the following sections I explore each of these areas in-depth, beginning with describing the issues within everyday interaction.

6.3 Everyday Interaction in Semantic Dementia

As I have outlined, whilst there were common recurring issues in the conversation data there was also considerable variability. The differences with interaction presented across the case studies was, in part, due to participants presenting at different stages of the condition and potentially may have been due to differences in left and right hemisphere presentations of semantic dementia within the brain (Mion et al., 2010; Seeley et al., 2005; Thompson et al., 2003). However, I do not have information from brain scans to examine the latter point further. Importantly, I have also presented differences in adaptation to changing interactional needs in both the person with semantic dementia and in family carers. Therefore, the variability present was not solely due to the differences in underlying language difficulty for the individuals with semantic dementia, but also a product of the social environment. This observation is consistent with other studies exploring interaction in the dementia literature (Hamilton, 2008a; Hydén et al., 2012; Jones, 2013; Mikesell, 2009a; Muller, 2003; Sabat, 2001). To date, such factors have not been explicitly examined in semantic dementia and this is a significant finding that is relevant for intervention because potentially the social environment can be changed through appropriate advice and support.

6.3.1 Language Difficulties in Conversation

The recent diagnostic criteria for semantic dementia (Gorno-Tempini et al., 2011) essentially focus on the language disorder evident in this condition, in particular symptoms of anomia or difficulty with finding words on confrontation naming tasks and difficulty with single-word comprehension tasks. In terms of spontaneous speech in semantic dementia, whilst Hodges and Patterson (2007) report that pauses in talk may occur as individuals struggle to find words, Neary et al. (1998) advise ‘the
patient does not search for words’ (p.51). In this study, regular and overt struggle to find words during conversation was only present for one participant (Peter) with other participants generally showing fluent speech, with increased use of pronouns, proforms and empty substitutions. Whilst both presentations arise from problems in systems of word retrieval, the labels ‘anomia’ or ‘word finding difficulties’ may be misleading. In my clinical experience, clinicians often understand this label as referring to overt struggle to retrieve words in talk, rather than fluent speech with a lack of content words. This means that at assessment such fluent difficulties in word retrieval may not be identified, unless specific and appropriate naming tasks are undertaken.

Issues of understanding, and misunderstanding, were evident in the conversation data with increasing problems in this area with progression of the condition. However, as I have illustrated, such difficulties were often displayed in a more subtle manner than may be expected given the current literature. For example, Kertesz (2010) reported that 34 out of their 37 participants with semantic dementia questioned the meaning of words heard in conversation and that this feature was a core and striking feature of the condition, although no detail was provided as to how this figure was derived. The findings of this study appear to be in contrast to this, with repeating words back evident on testing but not a prominent issue within the conversation samples. In this study, problems with understanding were more often displayed by the lack of an expected verbal or physical response. The findings are more in keeping with a study by Mikesell (2014). Here, she examined understanding in behavioural variant frontotemporal dementia and noted that individuals on the surface often appeared to understand; however, when a demonstration of that understanding was required, and this demonstration did not occur, failure in understanding then became apparent (Mikesell 2014).

Together, the findings across expressive skills and understanding indicate that the underlying language difficulties evident in single word production and comprehension tests may be displayed differently within everyday conversation. This has important implications for identification and management of the condition, as in my experience not all individuals receive detailed cognitive assessment within memory clinics.
6.3.2 Conversation Challenges

I have outlined in the previous chapter the conversation challenges present in the data and I will now explore the current literature with respect to each area as follows:

1. A lack of conversation.
2. Reduced repertoire of topics of conversation.
3. Repetitive questions.

1. A Lack of Conversation

I have illustrated that a recurring report by family carers in the first three case studies, and evident in the video data, was that the person with semantic dementia did not initiate topics like they used to, with a lack of conversation being a prominent complaint, particularly with progression of the condition. Individuals with semantic dementia have, however, most often been represented in the literature as talking too much, rather than not enough. Talk, for example, has been portrayed as garrulous, or disinhibited (Kertesz et al., 2010) or individuals described as having a press of speech (Neary et al., 1998). Here, therefore, this lack of conversation presents as a finding in contrast to the current knowledge. Ruby is the only participant that could be described as garrulous, although she is also described as talking less than she used to, particularly at home. In all cases carers reported that the person was more talkative in other settings or with a third party present.

It would, therefore, appear that both stage of semantic dementia and context influenced this issue and, perhaps predictably, that the person with semantic dementia may talk more or less in different situations. In terms of clinical practice, this study suggests that it is important to probe, either directly through video analysis or through interview, whether conversation may be different when the researcher or clinician is not present and it should not be assumed that the person behaves as they are in the current situation, in all others. This is also important in care planning processes. Organisation of appropriate activity for the person with semantic dementia may provide important opportunities for conversation not currently available and so enhance participation in everyday life.
2. **Reduced Repertoire of Topics of Conversation**

I have described the reduced repertoire of topics present in the talk of Peter, Sarah and Ruby and also present for Doug in the past data set (Kindell, 2011). Repetition of topics was reported to be part of the theme of ‘living with routines’ in earlier data with Doug and Karina (Kindell et al., 2014b) and this also presents as a theme in these three other cases, whereby family carers had become accustomed to these recurring topics and practices in conversation.

Whilst the literature has made mention of perseveration of themes in conversation in semantic dementia (Hodges and Patterson, 2007; Kertesz et al., 2010; Neary et al., 1998) this has almost exclusively been presented as a problem behaviour or a behaviour that the carer has to learn to live around (Kindell et al., 2014b); such phenomena have not been explored from the perspective of the person with semantic dementia. The data in this study are viewed from various perspectives and illustrate that the participants with semantic dementia often derived a great deal of pleasure and social stimulation from engaging in such personally related topics, using animated verbal and embodied behaviours.

Smith (2010) also noticed that there was a ‘person specific bias’ (p.65) in his conversation data with people with frontotemporal dementia, for example the tendency to turn topics to themselves. Within the substantive literature review, and threaded throughout this study, is an underpinning view of conversation as involving issues of both transaction and interaction. Viewed from a transaction perspective such topics convey information, but this information is already very well known to the carer. However, such topics can also be considered for their social function, beyond information exchange, that they hold for the person with semantic dementia by enabling them to take an active part within the interaction, using the skills they have available. As Smith (2010) argues, whilst on the surface such behaviour may appear to be self-centred, it may arise because the person no longer has access to other forms of experience. The data here echoes this point, for example Sarah can tell the story of her first job in detail, but has no recollection of other events from that time. The data here, therefore, adds to the work of Smith (2010) by highlighting the value such topics hold for involving the person with semantic dementia in interaction.
3. Repetitive Questions

In two case studies (Peter and Joanna, Sarah and Reg), repetitive questions from the person with semantic dementia, often surrounding the day’s routine, were a source of considerable challenge for the carer. However, there is little mention of such behaviours in the therapeutic literature targeting communication in semantic dementia and no reference is made to this issue in the most recent diagnostic criteria (Gorno-Tempini et al., 2011). In contrast, repetitive questions have been described within studies examining behaviour in semantic dementia, in particular as part of ‘clockwatching’ (Snowden et al., 2001). Repetitive questions and comments surrounding medication were also described in conversations with an individual with frontotemporal dementia, who had a previous diagnosis of semantic dementia (Mikesell, 2010a; Torrisi, 2010). Carers were described as using a variety of strategies including reasoning, distraction (e.g. changing the topic of conversation) or physically guiding the individual (Mikesell, 2010a; Torrisi, 2010) and there was some overlap in the strategies used by carers in this thesis, with Reg being particularly adept at distracting Sarah. More detailed exploration of this area in Peter’s talk indicated that he was using questions about the routine, e.g. “so what are we going to do today?”, at least in part, as a tool to initiate interaction. This behaviour, therefore, had both cognitive and social aspects, appearing to be Peter’s way to initiate a topic of conversation, given the reduced repertoire of tools he had available to do this. This indicated that giving an outline of the day and then leaving the conversation to go silent would not reduce this behaviour; in fact this was shown to lead to further questions. The strategy to manage such issues lay with distraction, either involving Peter in conversation or an activity.

Written reminders were used by carers to manage such questions, but this study indicates that this had limited success for these individuals. Joanna had tried to use a board in the kitchen with reminders about the day’s activities but Peter failed to go and check the board. Reg used written reminders placed directly on the table in front of Sarah and this helped to a certain extent but did not eliminate such questions; Reg is observed to answer each question directly, generally briefly and repeatedly, with a great deal of patience.
6.4 Adaptation to Conversation Changes

I have described how issues of adaptation were a recurring theme within this study. Adapting to changes in communication occurred for the person with semantic dementia and their family carers and this impacted on broader issues within relationships. Adaptation has not been explored in the semantic dementia literature, apart from earlier case study data with Doug and Karina, both within conversation (Kindell et al, 2013) and carer narratives within the theme of ‘being adaptive and flexible’ (Kindell et al., 2014b). Therefore, findings from this current study around adaptation build on this earlier work to contribute to enhanced understanding of everyday life with semantic dementia and the place of intervention to facilitate adaptation. I will now examine each area in turn and relate this to the current state of knowledge in semantic dementia and the broader dementia and aphasia literature.

6.4.1 Adaptation – The Person with Semantic Dementia

Adaptation to communication difficulties through the use of compensatory strategies has been noted in aphasia and non-fluent primary progressive aphasia by Simmons-Mackie and Damico (1997) who defined such strategies as ‘a new or expanded communicative behaviour, often spontaneously acquired and systematically employed, to overcome a communication barrier in an effort to meet both transactional and interactional communicative goals’ (p.770). Therefore, some strategies might be trained or deliberate on the part of the person, whereas others are spontaneously acquired, natural adaptations. As I have illustrated in Chapter 5, there was evidence of both types within this data set. For example, Peter’s habit of writing a daily journal had been taught. However, his habit of physically showing items to support his telling appeared to be a spontaneous expanded behaviour, i.e. a phenomenon present in normal conversation, but used more often to meet increasing communication needs (Simmons-Mackie and Damico, 1997). Peter’s habit of repeatedly asking questions about the routine, after a lull in the conversation, is perhaps another example of a naturally occurring adaptive strategy. Whilst this may reflect problems with his memory, the behaviour in context also presents itself as a strategy to start up conversation following a period of silence and, in addition, illustrates some social awareness on Peter’s part that conversation is required. Time has been described as an area of relative preservation in semantic dementia that the
person may draw upon, providing a meaningful reference point in their world (Snowden et al., 2006) and this may, in part, explain Peter’s pre-occupation with the routine of the day. In other circumstances this may be an appropriate conversational opener, however, the repeated presence of the same question within the same conversation, caused considerable difficulty for Joanna.

This study has also explored Doug’s recurring practice of enactment in conversation in a longitudinal design. Currently, there are no longitudinal studies of natural conversation change in semantic dementia and this study, therefore, presents unique insight into this area. In the earlier study Doug was shown to use direct reported speech, pitch, loudness, facial expression and body movements to act out, or depict, scenes within the conversation and this was presented as a form of adaptation (Kindell et al., 2013). In the later data set presented in this thesis, Doug continued to use direct reported speech, appearing to act out conversations using the same resources, however the decline in his language skills made it harder to follow his speech. In addition, he was now engaging in a number of other behaviours of a performative nature within his talk, including singing, claps and foot stamps and his upper class accent, a theme I will return to later when I explore more fully issues of performance. The data here, therefore, provides further evidence to support the initial analysis and illustrates how this practice has evolved with time (Kindell et al., 2013).

In Ruby’s conversations there was again the repeated use of direct reported speech and other enactment behaviours to convey the events and the mood of the scene she was telling. Direct reported speech is a common feature within conversational storytelling, including stories of complaint which were common in Ruby’s talk (Selting, 2010). It has been argued that direct reported speech and enactment is a useful resource for people with aphasia because it allows a speaker to depict multiple aspects about a story or an event, including expression of emotion, rather than have to tell about it and, therefore, presents as a linguistically simpler and more efficient practice (Wilkinson et al., 2010a). Brian was unable to say if Ruby had always told stories in this way so it was hard to ascertain if this behaviour arose because of an increase in storytelling itself or a change, or adaptation, in conversation practices within storytelling. However, the significant presence of this in her talk, given Doug’s earlier data, is intriguing and raises the question as to whether enactment and
direct reported speech is a form of adaptation in others with semantic dementia. Longitudinal data collection with Ruby would have been interesting to uncover if such features persisted with time, or were used differently in the future to track such potential issues of adaptation.

The definition provided by Simmons-Mackie and Damico (1997) provides a helpful explanatory definition for the behaviours of adaptation present in this study and is particularly helpful for those with more advanced dementia where strategies are natural, adaptive responses and success was more about interactional goals than transactional goals. In some respects this also has echoes of the initial stages of the bio-psycho-social model (Sabat, 2008) where the person’s reaction to the changes in their cognition is an important part of the model. However, in the bio-psycho-social model such reactions are often assumed to be psychological reactions, whereas here I have described reactions in terms of individualised adaptive communicative responses.

Whilst Simmons-Mackie and Damico (1997) present such behaviours as helpful adaptations, the data from Ken raises the possibility that some adaptations by the person with semantic dementia might also have negative consequences or be potentially maladaptive. So, Ken’s habit of testing his own knowledge of painters and paintings appeared a conscious strategy to maintain this important knowledge; however, this also had a damaging effect on his self-esteem.

6.4.2 Adaptation within Interaction – Family Carers

Adaptation here refers to changes family carers made in their conversations to accommodate the communication needs of the person with semantic dementia. Signs of positive adaptations were present in all carers, however, there were also areas where carers appeared to struggle or were using practices that appeared unhelpful, or maladaptive, within the interaction. There were a number of areas in relation to this and I will now describe each of these.

**Comprehension:** I have illustrated the ways that carers reported and were shown to manage problems with comprehension. Whilst such difficulties, particularly
understanding single words on testing, have been highlighted in the literature (Gorno-Tempini et al., 2011; Hodges and Patterson, 2007) and some advice is available derived from clinical experience (Snowden et al., 2006), there appear to be no studies developing evidence based guidance grounded in real life data. Interestingly, whilst some of the strategies reported by carers were similar to common guidance for dementia in general, such as keeping talk simple (Ripich et al., 1999), there were some strategies that appeared to be more specific to this client group, including using visual means such as the use of Google images on an iPad to explain specific vocabulary and explaining place names through using recent personal and sensory experiences. ‘Enriching the message’ was used within intervention to explain the addition of this extra detail. This study demonstrates a variety of innovative solutions to problems with understanding and suggests that further exploration of this area is important to ensure strategies are appropriate to this client group.

**Test Questions and Repair:** I have illustrated how test questions were used in three of the case studies, but also that whilst this was problematic in one case this appeared to be a helpful strategy in the other two cases. The long sequences arising from test questions and attempts to cue Peter to say particular words or express certain ideas were problematic. Such carer behaviours have been termed ‘pedagogic behaviours’ in studies of aphasia using conversation analysis because of the teaching nature of such interactions (Lock et al., 2001; Simmons-Mackie et al., 2014). Taylor et al. (2014) describe test questions as unhelpful in their conversation data in primary progressive aphasia. Shakespeare (1998) also presents a negative view of test questions, describing them as one of the ‘unusual things’ that ordinary members of society ‘take license’ to use when talking to confused speakers (p.215) and that this is evidence of them assigning less-than-full-membership (Sacks 1972) to society for people experiencing confusion. Rippich et al. (1999) state in their advice for carers of people with Alzheimer’s disease: ‘do not ask test questions’ (p.55).

Such sequences are relatively rare in peer interactions in normal conversation, occurring more commonly in interviews or the classroom, where three-part sequence types of question-response-evaluation are more acceptable (Scheglof, 2007). Scheglof (2007) observed that the use of test questions has social consequences
when used outside of these situations because the recipient of the test question may feel demeaned and therefore this may present as a threat to face (Goffman, 1955; Goffman, 1967); this was observed in this study in Peter’s case. In addition, in normal conversation there is a preference for self-initiation and completion of repair of conversational trouble and for repair sequences to be short, avoiding a lack of competency being overtly displayed (Schegloff et al., 1977). Unfortunately, the strategy Joanna used to encourage Peter was in direct conflict with this preference because she initiated and often completed the repair, but only after much searching on Peter’s part. This overtly displayed Peter’s lack of competence and was frustrating for them both.

However, I have also illustrated how test questions appeared to be helpful for Sarah and Reg, and Doug and Karina. In these instances Reg and Karina appeared to be using such questions as a device to invite Sarah and Doug into the conversation. The use of test questions for this purpose has been noted in agrammatic aphasia with such questions presenting as safe ground when communication difficulties are present because both parties have equal access to the knowledge required to answer (Beeke et al., 2013a). Beeke et al. (2013a) conclude that, in contrast to test questions aiming to stimulate or practice particular vocabulary items, ‘the main motivation for using test questions in these data is to scaffold the person with aphasia in joining in with a new topic of conversation’ (p.801). Mikesell (2009b) also noted the presence of test questions in her data with individuals with behavioural variant frontotemporal dementia, arguing that this most often represented carer attempts to encourage participation.

Interviews in this thesis explored the perceived motivation of carers with respect to test questions, an aspect often lacking in research to date, where data is usually presented from interactions only. The carer reports here indicated that test questions served an important purpose where significant communication and cognitive difficulties were present in semantic dementia. For example, the interviews from Reg confirm that he used such devices deliberately to encourage Sarah to talk, saying: “I know the right buttons to press to make her say these things” (I 22/07/13). Both Reg and Karina reported that a lack of conversation was a recurring problem in their lives and so challenges arose, not only from dealing with the language disorder within the
conversation, but also from initiating conversations in the first place. By using test questions, Reg provided a topic for Sarah and set her off on a conversation that he knew she could achieve. In addition, the purpose was not transactional, it was not new information to Reg, the purpose was interactional, to make a connection for, and with Sarah, and in the process support her identity, as he says “if I don’t give her those, what has she got? Because she won’t come up with something herself” (I 22/07/13).

This study is the first study to explore issues of test questions across a group of people with semantic dementia, or indeed dementia of any kind, and indicates that such questions can be used for different purposes with different underlying issues of language and cognition and that examining their use in context is required. Moreover, carer narratives, alongside interactional data, provide unique insights into potential motivations and perceptions around interaction not currently present in the literature.

**Memory and Tag Questions:** Memory, and in particular recent memory, is often referred to as spared in semantic dementia, however, such statements are based on assessments of those in the earlier stages, where differential diagnosis is generally the focus of assessment (Gorno-Tempini et al., 2011; Hodges and Patterson, 2007). As I have discussed, the therapeutic literature in semantic dementia tends to focus on the language disorder evident in the condition rather than other areas of cognition and I could find no literature giving evidence based advice on memory difficulties in semantic dementia. As I have shown, Reg and Karina used a recurring practice of making a statement followed by a tag question to circumvent difficulties with memory.

The interactional management of memory difficulties has been explored in family conversations in Alzheimer’s disease by Jones (2013). This study describes some of the challenges arising not just from the memory problems that May, the woman concerned displays, but also arising from the numerous questions posed by family members that require skills with recent memory, which May does not possess. Jones (2013) does not discuss alternative strategies in this paper, however, in her doctoral thesis (Jones, 2012,) she advises to avoid questions that rely on memory and keep
questions in the direct here and now, advocating the use of the ‘Contented Dementia’ approach (James, 2008) where not asking direct questions is the rule.

In this study Sarah and Doug, likewise, exhibit significant problems with memory but the formulations used by their carers appear helpful, functioning as gentle and embedded ways to circumvent the memory failure. Information is given in a statement, avoiding placing the person with semantic dementia in a position to recall information or mark the memory problem in the conversation. The tag question then functions as a device to draw the individual into the conversation and the data illustrates a variety of appropriate responses. Reg and Karina’s use of this practice of ‘state and draw in’ reflects the way they design their turns to enable conversation about recent events in a manner that does not require Sarah or Doug to recall the event themselves.

Heritage (2012) discusses how individuals in normal conversation display the various rights to knowledge within the conversation and how tag questions can be used to display shared knowledge, but in a format that also acknowledges the rights of the other party to that knowledge. It could be argued that the formulations used by Reg and Karina display sensitivity to Sarah and Doug’s memory problems, by giving them information in a formulation that does not threaten to expose a lack of knowledge about their own experiences (arising from their memory problems). For example, Reg says to Sarah “so you didn’t have a good night’s sleep last night, did ya?” Sarah’s sleep the night before is her own experience and she, therefore, under ordinary circumstances would have primary rights to comment on this (Heritage 2012). This formulation displays sensitivity to this and represents an important adaptation to manage self-esteem in the context of memory failure. Interestingly, the data also show Joanna using such formulations at times in the post therapy data, for example, when she asks Peter a test question about where the family have gone on holiday, rather than pursue Peter to say the particular word, she uses a statement followed by a tag question: “they’re in Wales, aren’t they” (V 18/08/13). A search of the literature revealed no exploration of the use of such conversation practices in aphasia or dementia and this is, therefore, an important finding relevant for both fields.
Reduced repertoire of topics of conversation: I have demonstrated that the carers of Peter and Sarah responded differently to the recurring topics evident in their talk. Studies have demonstrated the importance of listener feedback in encouraging individuals with dementia to continue with a story using such behaviours as emotive and evaluative responses, e.g. ‘that’s good’, continuers, e.g. ‘mmm’ and news-marks, e.g. ‘you don’t say!’ (Davis and Maclagan, 2014; Hydén et al., 2012). Hydén (2013; 2011) argues that conversational storytelling is a collaborative activity in dementia, with family carers providing ‘narrative scaffolding’ to help the person with dementia tell their story. Within this thesis there is both the presence and the absence of listener feedback and narrative scaffolding.

It is, however, worth highlighting the differences in circumstances for conversation in such studies. In some, the couple are both involved in telling a story to a third party such as a researcher (Hydén, 2011; Hydén, 2013), in others the person with dementia is telling their story to a researcher, member of staff or another person with dementia (Davis and Maclagan, 2014; Hydén et al., 2012). There is a lack of exploration of the scaffolding of stories when a couple are at home on their own, which is the case for much of the video data here recorded in case studies one and two. Researchers, for example, are interested in gathering a language sample and so are less likely to point out that a story has been told before. It might be understandable that news-marks might be used less by family carers who have heard a story many times over. Lastly, telling a story together to a third party might be more likely to facilitate collaboration.

Given, however, that there is a difference in how the two carers in case studies one and two respond, then the issue here is not just about couples talking alone. Wray (2014) makes some interesting observations that are relevant to this issue in her discussion of carer responses to formulaic language in dementia, which has many parallels with the recurrent stories evident in semantic dementia. She argues that there is a dilemma for carers in whether to treat and respond to such utterances as though they are ‘normal language’ or ‘abnormal language’. It could be argued that Joanna views Peter’s stories using the lens of normal conversation, and particularly issues of transaction. Therefore, because Peter’s stories do not present as new information to her, it is not necessary to facilitate them further and the conversation
turns to other matters. Reg, in contrast, seems to have accepted that the ground rules have changed and he indicates that his purpose in engaging Sarah in such topics is to keep her involved, i.e. for purposes of interaction. Wray (2014) argues for empathy-training that helps carers to see what functions the formulaic language is having for the person with dementia. Again, this data indicates parallels in that such work may be important to help some carers understand what functions repetitive topics and stories have for the person with semantic dementia and by doing so, encourage tolerance of such behaviours. This may involve explaining that whilst information transfer is limited, the value in such topics lies within the realm of interaction, social relationships and well-being of the person with semantic dementia.

Family carers also reported that their reaction to repeated topics and other repetitive behaviours depended on the context, with particular vigilance required when out in public. This was also in keeping with the theme of policing and protecting reported in Doug’s earlier data, whereby carers would police interactions in order to step in to help or smooth over any unwanted behaviours (Kindell et al., 2013). There was also overlap with carers’ explanations of behaviour within the theme of defending, asserting and explaining reported by Oyebode et al. (2013) in behavioural variant frontotemporal dementia. These contextual issues raise questions about how friends, neighbours and the wider community can support, or not, an individual with semantic dementia and their carer. Reg gave a particularly good example of this, describing how Sarah sometimes sung loudly when they were out in public and so they were careful where they went. However, when they went to the café in a certain market, if Sarah did not sing, the women there would ask what was wrong and encourage a song from her (I 06/01/14). The carers in the study by Oyebode et al. (2013) reported ‘havens of peace, away from the possibilities of social embarrassment’ and whilst some construed this as literal havens from the world, others as in Reg’s case here, referred to the ‘non-judgemental acceptance’ of others (p.161). Whilst Ruby and Brian’s situation was particularly influenced by their desire not to tell others about Ruby’s dementia, it does raise issues of whether such ‘empathy-training’ might be relevant to a person’s wider social network, including friends. This kind of work in semantic dementia was noted by Kindell et al. (2015) where therapists’ work involved the wider friendship group, including meeting with friends to facilitate this process. Further examination of the management of recurring
stories and other repeated conversational behaviours from those with semantic dementia, both at home and in the community, would appear to be a useful line of enquiry for further research.

6.4.3 Adaptation – Broader Issues for Relationships

A number of studies in the general field of dementia care have explored how couples and families adapt to life with a dementia, with a focus particularly on relationships (Hellström et al., 2007; Keady and Nolan, 2003; La Fontaine and Oyebode, 2014; Molyneaux et al., 2011; O'Connor, 2007; O'Shaughnessy et al., 2010; Purves, 2010; Roach et al., 2014b; Wadham et al., 2015). Issues of tension and complexity are identified within this literature. For example, tension may exist between the needs of the spouse and the person with dementia (O'Connor, 2007; O'Shaughnessy et al., 2010). Different ways of ‘working’ or being a couple in the face of dementia and its progression have also been identified with some couples working together in the face of dementia and others working apart and different strategies being reflected at different stages of the process (Hellström et al., 2007; Keady and Nolan, 2003; La Fontaine and Oyebode, 2014). Roach et al. (2014a; 2014b) demonstrated different storylines in families living with younger onset dementia: agreeing, colluding, conflicting, fabricating and protecting.

Two reviews have been carried out to examine the qualitative literature examining relationship issues in dementia. Wadham et al. (2015) examined couples’ shared experiences of dementia and found four overarching themes: 1) Togetherness: continuing as we; 2) Upsetting and re-defining: A new ‘normal’ is evolving; 3) Sensitive attunement: Shielding one’s partner from the effect of dementia; 4) Resilience: Distancing distress whilst cherishing life and the present moment. La Fontaine and Oyebode (2014) examined couple and family relationships in dementia and identified four superordinate themes that could then be broken down further into both positive and negative poles: 1) A shared history – A good life together, disconnectedness; 2) Negotiating the impact of dementia upon the relationship – A problem shared, working apart; 3) Openness and awareness – making meaning, minimising; 4) Shifting sands – shifting responsibilities, time together and time apart, loss. Both reviews, therefore, highlight the way couples negotiated the impact
of dementia on the relationship and strived to maintain a sense of connection and relationship as a couple, with some similar themes. However, the review by La Fontaine and Oyebode (2014) has a great sense of the challenges that some couples experience in this task.

In their review La Fontaine and Oyebode (2014) identified that much of the couple and family literature is based on interviews with couples and families reflecting on their situation, and their relationship, with relatively few studies examining live interactions to explore relationships (Clare and Shakespeare, 2004; Molyneaux et al., 2011; Purves, 2010) with only the study by Purves (2010) aiming to gather natural interactions. There are, therefore, significant gaps in understanding within the literature. Interestingly, O’Connor (2007) noted that her use of narratives alone, without direct observation of dynamic natural interaction, limited understanding of how carers position themselves as ‘carers’ or ‘spouses.’ In contrast, this study explores narratives of those living with semantic dementia and their spouses as well as direct observation of natural conversations at home. Data is gathered from descriptions of relationship issues as well as providing a window into in-the-moment performance of relationships in conversation. As I have discussed, the triangulation of this data indicates a fruitful line of enquiry for both this study and future research in examining the complexities of daily experience in dementia, with a focus on what is being achieved within interaction, tied with exploration of the broader context of the lived experience. Whilst ethnographic data has been gathered alongside interactional data in frontotemporal dementia (Mikesell, 2009a; Mikesell, 2014; Smith, 2010), the purpose of this has been to foster analysis of the interaction, using conversation analysis, not to examine the context of talk or relationships. This study therefore presents with an innovative design to study experience in semantic dementia and other dementias.

The approach in this project has demonstrated the complexities of interaction and the many dilemmas threaded throughout the daily experience that impact on relationships. I have demonstrated that Sarah and Reg, and Doug and Karina appeared to be working together in the face of dementia with a sense of connection and togetherness, themes identified in the literature (Keady and Nolan, 2003; La Fontaine and Oyebode, 2014; Wadham et al., 2015). This study also provided
additional interactional data to confirm this sense of connection was also present within the in-the-moment performance of relationships in conversation for these couples. In both cases the carers had developed conversation practices to involve their partner in interaction despite significant communication difficulties and advancing semantic dementia; also showing elements of shielding their partner, in interaction, from the effects of the dementia (Wadham et al., 2015). La Fontaine and Oyebode (2014) have argued that positioning the problem as the dementia, rather than the person, may be a positive factor in relationships and coping with dementia, and this would appear to be the view that the carers Reg and Karina held.

In contrast, Peter and Joanna, and Ken and Brenda, presented with conflicting views about their situation, closer to the conflicting storylines reported by Roach et al. (2014a; 2014b) in younger onset dementia or the pattern of working apart described in other studies (Keady and Nolan, 2003; La Fontaine and Oyebode, 2014). Again, the presence of conflict and frustration was also evident within interaction with both couples. For Peter and Joanna, interaction-focussed therapy worked directly to change patterns of interaction and reduce frustration. With Ken and Brenda, one focus of therapy was dealing with their different views about the dementia. When talking together, Ken would emphasise how challenging his symptoms were and Brenda would attempt to reassure him. However, this made Ken feel that Brenda was minimising his difficulties and therefore not supporting him, leading to further disagreements. The lack of any significant linguistic or cognitive difficulties observable within the data indicates why Brenda might attempt to reassure Ken, particularly given her worries about his reaction to his diagnosis. Within the intervention, this was not about determining who was right, but about dealing with this conflicting viewpoint. Following discussion, Brenda reported a move away from this strategy as it only led to disagreements. Minimising was a theme noted by La Fontaine and Oyebode (2014) arising particularly in studies which utilised methodologies that focussed on live interactions. It could be argued that minimising, particularly within interactions, might in some instances occur where carers are concerned that an individual’s psychological state is fragile, as Brenda worried about Ken. This may also relate to attempts to preserve face within interaction (Goffman, 1955) an important factor to consider in studies examining live interaction that is not an issue when interviews are carried out separately.
Ruby and Brian’s case presented particular challenges because of Ruby’s reluctance, for whatever reason, to talk about her dementia, as well as their attempts to conceal her diagnosis from others. Perry and O’Connor (2002) note the work that goes into supporting the person with dementia’s competence and protecting from incompetence, along with the problems inherent in attempts to present a normal façade to the world. Despite recent advances in dementia awareness, issues of stigma clearly remained for Ruby and Brian. Goffman (1963) describes stigma arising from mental illnesses, with stigma being described as a social process whereby the reaction of others is crucial in the spoiling of identity. This encapsulates the worry that Ruby and Brian expressed about Ruby’s social identity and how if they told their friends they may react differently to her. Goffman (1963) discusses the lengths individuals will go to in order to pass as a ‘normal’ member of society and gain acceptance, therefore avoiding stigma and, like Ruby and Brian, this involves control of information and active behaviours of interactional concealment. However, whilst Ruby and Brian were in agreement not to tell their friends, within interaction Ruby was less able to spot the signs that she might be failing to present a competent façade. As a result the work, and stress, to achieve the concealment largely fell to Brian. Concealment behaviours of this nature have been identified as potential sources of stress in those with chronic disease (Joachim and Acorn, 2000) and Brian too found interaction with others difficult at times. Issues of covering up and working separately within couples living with dementia are discussed by Keady and Nolan (2003) in their analysis of the management of the early signs of dementia within the relationship. The data here highlight similar issues, but rather than being intra-couple, the couples are placed within a social arena and the exposing nature of interactions becomes apparent. The work to achieve the concealment cannot be done by Ruby and so Brian has no option but to work alone on this matter.

Perry and O’Connor (2002) describe the dilemma faced by carers in their interview data, with carers differing in the definition of personhood they were trying to preserve: ‘the person prior to dementia or the person with dementia’ (p.60). Whilst Joanna and Brian, particularly in social situations, appeared to be trying to preserve the person prior to dementia, Reg and Karina appeared to have reached a level of acceptance and they were attempting to preserve the personhood of the person with dementia.
The quality of the past relationship has often been highlighted within the dementia literature as a factor relevant for current coping (Ablitt et al., 2009; La Fontaine and Oyebode, 2014). There is, therefore, a temptation to make a connection between current conversation practices, as evidenced in this data, and the quality of the past relationship, for example, that a strong relationship in the past would naturally lead to greater adaptation within interaction in the present. However, for the individuals in this study, the picture was more complicated. Peter and Joanna reported a very strong and close relationship in the past, yet were experiencing high levels of difficulty now within interaction. In direct contrast, Doug and Karina had experienced many testing times across the course of their marriage and so, given their history, it was perhaps surprising how well they had adapted, with Doug remaining at home for a long period with semantic dementia. Whilst Joanna reported a constant and overwhelming sense of grief at the loss of their prior relationship, Karina, in contrast, felt sad for Doug and that caring was hard, but she did not mourn for the past in the same way.

6.4.4 Summary Adaptation
In summary then, the data here provide insight into how those with semantic dementia and their families adapt to living with this condition, including exploration of in-the-moment performance of relationships through direct observation of interaction. Analysis indicates that the theme of ‘being adaptive and flexible’ described within Doug’s earlier data set (Kindell et al., 2014b) was an underpinning dynamic in other couples too living with semantic dementia. In addition, for some individuals and couples a natural process of adaptation had occurred, however, others found being adaptive and flexible much more difficult and this was evident in their interactions and their interviews, with patterns of maladaptive behaviour and barriers to adaption.

The literature indicates that caregiving in dementia is multifaceted and complex with different levels of adaptation in the face of this adversity and this is reflected in the literature examining resilience in family carers (Dias et al., 2015). La Fontaine and Oyebode (2014) caution that the desire to move away from models of stress and burden should not obscure the negative experiences reflected in their themes of
disconnection, working apart and minimising and the need for further research in this area. Such research examining issues of adaptation is particularly relevant to workers in older people’s mental health services who are likely to be engaged in supportive interventions, sometimes for prolonged periods, with those couples who are struggling to adapt to life with dementia. Providing interventions and advice around interaction is a vital aspect to this work and this chapter now turns to the interventions delivered in this study.

6.5 Intervention: Interaction-Focussed Therapy

Whilst the reaction of others within conversation has been highlighted as a major influence on the interactional performance of a person with dementia (Jones, 2013; Perkins et al., 1998; Ramanathan-Abbott, 1994; Sabat, 2008) this has not been effectively translated into individualised intervention, as it has in the field of aphasia therapy (Lock et al., 2001; Simmons-Mackie et al., 2014; Wilkinson et al., 1998). Thus, interaction-focussed therapy has not been researched in dementia care and this study presents as the first attempt to explore this in any kind of dementia. The case study with Peter and Joanna showed that interaction-focussed therapy could be delivered in a dementia context. Improvements in interaction could be measured post-therapy within conversations recorded at home, demonstrating changes in pedagogic behaviour in facilitating known responses and target words, with explicit mention of errors and repetition.

There were, however, some adaptations to the method in practice. Narrative interviews allowed for a deeper understanding of Joanna’s behaviour including the profound sense of loss that she was feeling. Interaction-focussed therapy, as a result, for this case had a greater psychological element to it than is often expressed in studies of aphasia therapy (Lock et al., 2001; Simmons-Mackie et al., 2014). Whilst the study did make positive changes, in my clinical opinion, I felt the intervention had been offered too late for Peter and Joanna and would have been more helpful at an earlier stage to prevent maladaptive behaviours becoming entrenched and reduce the emotional distress they were both experiencing. Further research is required to explore how such approaches can be contextualised to the needs of dementia care practice.
Interaction-focussed therapy, as envisaged in the research protocol, was not
delivered in other cases. In case studies two and three the couples showed evidence
of natural adaptation in conversation, with many positive behaviours already evident
within their interaction and so changes to their interational behaviour using
interaction-focussed therapy was not indicated. Another study using video data
(Gallagher-Thompson et al., 1997) noted that their sample of couples appeared to
have above average adjustment to the dementia and argued that this may, in part, be
due to the selection process of the research, for example, with couples who are
struggling to adapt less likely to volunteer for such studies. Therefore, when using
video within research projects in dementia, particular attention may be needed to
recruiting diverse experiences in terms of adaptation, coping and relationships. In the
last two cases video recording interaction when the couples were alone proved
problematic although they were both happy to record with the researcher present and
I now turn to some of the challenges with video.

6.5.1 The Challenges with Video Recording

Video recording, rather than audio recording has been recommended in dementia
care in order to study embodied interactional behaviours (Hydén, 2013), however, in
such studies, recording often takes place with the researcher present (Ellis-Gray et
al., 2014; Hydén, 2013) or with more controlled tasks identified for recording
(Gallagher-Thompson et al., 1997). Other studies have noted some challenges with
using video to record interaction at home in dementia, including issues of
recruitment (Ellis-Gray et al., 2014; Gallagher-Thompson et al., 1997). Within the
aphasia interaction-focussed literature and the initial design of this study, the aim is
to record interactions that are as close as possible to natural interaction, and
therefore, interactions are recorded without the researcher, as this alters this natural
dynamic. This approach has been relatively rare so far in dementia, with few studies
exploring face to face interaction with family members without researchers also
present (eg: Kindell et al., 2013; Perkins et al., 1998; Purves, 2010).

All of the couples in this study expressed concern that they would find it hard to
think of things to talk about while the recording took place and whilst some
suggestions were given in the written materials, participants found the open ended
nature of the study protocol of ‘talk about anything you like’ particularly problematic. Interestingly, the first three couples reported that they no longer held casual conversations and talking now only occurred during activities or the daily routine. Some of the recordings couples made were of this nature, e.g. recordings during meal times or other tasks, but the recordings did contain some casual conversation alongside. It seems likely that recording natural unstructured conversation is particularly problematic for those with memory problems, or difficulties with the initiation of ideas as in semantic dementia, because such cognitive difficulties impact on the very foundations of conversation, i.e. the initiation of conversation. It was important to allay anxieties and state that the aim was to video normal life and if normal life contained only fragments of conversation, interspersed with large periods of silence, this was exactly the thing to record. Reducing the pressure to talk, particularly in cases one and two, actually led to the recording of significant amounts of interaction.

Research largely prevents a staged process of engagement, as would occur in clinical practice, with all tasks outlined prior to involvement and consent obtained. Whilst I was able to use some flexibility with this, the design of the interaction-focussed work meant that the task which participants found most daunting was the task first required of them, before we had established a relationship. In addition, within the consent process, participants were asked if their video clips could be used for teaching and for some this further added to their anxiety. So, for example, initially Ruby and Brian did not want their videos to be used for teaching, but in later sessions reported that they were now happy for this to occur, presumably because trust had developed between us. Lastly, participants were asked to record conversations over a period of three weeks, 20 minutes per week, either in a continuous stream or in shorter bursts to give 60 minutes of conversation in total and whilst for some this was achievable, for others, with more significant communication difficulties, this proved daunting.

For future studies of interaction-focussed therapy in semantic dementia, or in using this approach in clinical practice, the following adjustments might be useful to facilitate participation in the research and reduce anxiety about video recording:
1. **Begin with video with researcher present** – to more explicitly state that video recording will begin with the researcher present and, if and when, the couple are happy to try themselves this will be carried out. For some this may present a graded experience and facilitate self-recording. For others still reluctant to video themselves, video recording with the researcher present, whilst not ideal, might facilitate access to interaction-focussed research and therapy. Post-therapy video comparison would, therefore, also be with video with the researcher present. For some individuals it may be possible for the researcher to set up the camera and start off the interaction but leave the couple for a short period while they record material on their own.

2. **Give explicit ideas of when to video within written material and reinforce when presenting the study** – for example to state ‘during a mealtime, having coffee, planning the day ahead or another time that you identify is convenient to you when some talking may occur.’

3. **Use video from other studies to illustrate recorded data** – to show where and when and illustrate that ‘mundane’ everyday conversation is the aim, in order to reduce anxiety over a lack of ‘interesting’ talk.

4. **Reduce the amount of video data gathered** – e.g. participants could keep the camera for two weeks and aim for 10 minutes each week.

5. **A process of reviewing video data after data collection to facilitate consent to use for teaching** – participants and the researcher to review and discuss video data, including why extracts might illustrate results of the study and demonstration of use of windows movie maker, or similar programme, to edit clips and present in anonymised ‘line drawing’ format for those who wish this.

### 6.6 Intervention - Life Story Work

Life story work was delivered in all five case studies. As part of this study, I reviewed current life story tools and templates used in clinical practice (Kindell et al., 2014a). Whilst there were a range of practice based resources providing advice, much of this lacked an evidence base or any step by step guidance for developing
individualised life story resources as products to support interaction. No practice based guidance or research was available for semantic dementia. Therefore, rather than use an existing template, the format for life story work followed from detailed exploration of each individual with semantic dementia’s current situation and needs, delivering a variety of life story products, in each case with individualised goals and outcomes. I will now discuss the various aspects of the life story work including: the format of products, the impact of cognition, the context for life story work, the goals and outcomes of the work.

6.6.1 Life Story Formats
As I have highlighted, in clinical practice and in the research literature, life story books dominate as the preferred format for life story work (Kindell et al., 2014a; McKeown et al., 2006; McKeown et al., 2015). Such books are often made, stored and accessed by carers and staff, with little guidance on materials made by, or controlled by, the person with dementia (Kindell et al., 2014a). This study delivered a variety of innovative formats dictated by personal need.

**Portable Pocket Life Story Resource:** Peter’s pocket life story book gave him a level of control and empowerment not evident in the current life story literature for people with dementia (McKeown et al., 2006; McKeown et al., 2015; Moos and Björn, 2006). Thus, portable life story resources owned and controlled by the person with dementia, present as an innovation to semantic dementia and the general field of dementia care.

**Life Story Music DVD:** The life story music DVD contained songs that were relevant to Sarah and her life story, but the focus was on the interaction provided by the song in-the-moment, rather than the memories associated with the song; the latter generally being the focus of music within life story work (Moos and Björn, 2006). So, for example, Sarah and Reg’s engagement song was used for them to sing along to together, rather than to reminisce verbally about the past memories associated with the song. The focus of both the intervention and its evaluation was therefore an exploration of changes in-the-moment for interaction.
Making Connections: This sheet for Doug focused largely on current activities and abilities that provided an opportunity for a social connection, thus moving beyond the need for information in conversation, into the realm of embodied interaction. Whilst I am aware of summary sheets in use in clinical practice, the literature makes little reference to the design or focus of such materials. Summary sheets present a different and efficient way to deliver life story information to others, e.g. care home staff, who lack the time required to read lengthy documents. However, it should be noted that the sheet was not merely a list of facts and a quick way to life story work because the information was underpinned by a detailed and longitudinal assessment of interaction.

Topic Based Life Story Books: Life story books were developed with Peter and Ruby but the books, in contrast to current literature and practice around life story work (Kindell et al., 2014a; McKeown et al., 2006; Moos and Björn, 2006), focussed on the present as well as the past and were ordered not in a chronological fashion but organised around those topics that engaged the person with semantic dementia actively and positively in conversation in the here and now.

Enriched Self-Generated Life Story Resource: The control and delivery of this activity, by the person with semantic dementia, rather than the carer or clinician, appears to present as a departure from the current life story literature (Kindell et al., 2014a; McKeown et al., 2006; Moos and Björn, 2006). In addition, the semantic dementia literature currently lacks any consideration of self-management strategies by people living with this condition and, therefore, provides important outcomes for research and practice.

6.6.2 Cognition and Life Story Work in Semantic Dementia
The data indicates that a bio-psycho-social focus is relevant for life story work, i.e. that it was important to consider cognition alongside psychological and social factors. For example, in contrast to the general life story literature which makes little reference to cognition, this project illustrated that individualised cognitive factors did impact on the process and product of life story work, including problems with
recognising faces and places in pictures, surface dyslexia and positioning of written material on the page.

There is also a central focus within life story work in dementia care on engaging the person with dementia in talking about their past life in order to influence current care (e.g. Clarke et al., 2003; McKeown et al., 2006; Subramaniamay and Woods, 2012) or talking with their spouse to influence their relationship (Ingersoll-Dayton et al., 2013). One of the appeals within this approach arises from the relative preservation of long term memories in comparison to recent memories evident in Alzheimer’s disease and, therefore, that individuals are often more successful in talking about topics from their long term past (Bourgeois et al., 2001; Ripich et al., 1999). In this thesis, the memory problems presented by participants were patchy, with retained memories appearing to be from both the long term past and recent memory, in contrast to the pattern evident in Alzheimer’s disease. It was, therefore, not possible to account for these issues on a simple long term versus recent memory distinction.

There is debate about long term and recent episodic memory in semantic dementia. Some studies have described the relative preservation of recent versus remote memories in the condition (Graham et al., 1999a; Hodges and Patterson, 2007; Hou et al., 2005), although it appears that with progression the situation is more complex, with changes in recent and long term memory evident (Matuszewski et al., 2009; Viard et al., 2013). However, such studies rely on researcher provoked memories in structured tasks, rather than those spontaneously recalled by the person with semantic dementia.

Snowden et al. (1994; 1995) and Julien et al. (2010) argue that personal experience influences retention of knowledge in semantic dementia, including vocabulary, such that individuals may retain low frequency words and concepts that are particularly relevant to them. Recently, Snowden (2015a) noted that people with semantic dementia may use words in context themselves that they then fail to understand on assessment; Snowden used earlier work by Funnell (2001) to argue that event scripts derived from personal experience may form a more resistant and context-bound aspect of meaning. Therefore, semantic memory should not be understood with reference to single words alone but that ‘it may encompass larger units of meaning that includes the goal-directed scripts of our daily lives’ (Snowden, 2015a, p.2). This
study indicates that such scripts may also include stories of autobiographical significance from the past. A cognitive view states that there is interaction between autobiographical memory and semantic memory in the retention of well-rehearsed scripts (Snowden, 2015b). Sarah, therefore, retains the story of her first job, along with words such as ‘machinist’ and ‘piecework’, because autobiographical memory is supporting the script and the vocabulary. However, a view from conversation analysis would consider a more distributed and co-constructed view of knowledge, including how the regular telling of this story within interaction recreates the episode in a social arena. It could be argued that this recent social event equally contributes to the retention of knowledge, rather than a purely cognitive state within Sarah’s brain. This study, therefore, provides important insight into cognition in action within everyday conversation in semantic dementia and presents as a first study to bridge the divide between psycholinguistic approaches and social approaches in semantic dementia, a recommendation for dementia outlined within the substantive literature review (Guendouzi and Pate, 2014; Hamilton, 2008a).

On a practical note, this study confirms the suggestion by Kindell et al. (2014a) that life story work in semantic dementia needs to be adapted to include more emphasis on recent information to reflect the different cognitive profile of the condition. This study goes further in identifying other cognitive issues with the use of photographs and the written word, indicating that assessment and piloting life story materials with the person with semantic dementia is important to address this. Lastly, for some individuals with advanced semantic dementia, their cognitive difficulties meant that prompting past memories to use in current conversation had its limitations and that finding creative ways to foster in-the-moment interactions was more realistic.

6.6.3 Life story work – Examining the Context
Considering the person’s social context(s) was also important, including with whom and how they would use their life story resource and this is not an area that is systematically explored in the life story literature. The data, for example, indicated that certain formats might be more successful in one family context than another. Considering how the life story format was to be used also influenced the development of the resource. So, for example, Doug’s resource was for staff rather
than him and so attention to issues of the positioning and simplicity of written material was less important, whereas for Peter, this was crucial and the portable resource was designed around his needs.

Whilst the initial study design had focussed on conversation at home, it was clear that interaction in other contexts could be influenced by the life story work and Peter’s portable book was an example of this. In addition, Peter’s established habit of showing materials and objects to support his telling meant that he adapted well to using this resource. Simmons-Mackie and Damico (1997) argue that therapy should begin with analysis of the spontaneous strategies already used by individuals with aphasia and build on those and this is, therefore, consistent with this approach.

6.6.4 The Goals and Outcomes of Life Story Work

As I have illustrated this study confirmed that the formulation developed by Kindell et al. (2014a) could be used to map these various points of connection:

- Interactional connections.
- Emotional connections.
- Practical care connections.
- Building new connections.

In addition, the data indicated there was also a fifth theme:

- Future connections.

I will now discuss each of these points of connection in turn with respect to the current literature. As I have already established there is no research specifically examining life story work in semantic dementia so current knowledge in the general field of dementia care has been used.

**Interactional Connections:** refers to the ability of a life story resource to ‘support memories and conversation around personally related topics and through increased shared knowledge can help to decode potentially empty speech’ (Kindell et al., 2013, p.159) and this study directly demonstrated this. Thus, the provision of the life story resource provided important ‘anchors’ for the story world (Hamilton, 2008b) for
Peter and Ruby. As I have discussed there was also a move away from a sole focus on a narrow view of communication as transaction, to one encompassing interaction. This presents as a departure from the life story literature, particularly that examining memory wallets/aids, where success is judged by time spent on topic and information conveyed from a particular topic (Bourgeois, 1993; Bourgeois et al., 2001; McPerson et al., 2001) or information retained generally, as in autobiographical memory function (Subramaniamay et al., 2014). Given that some studies have shown that memory wallets may not be as helpful for those with advanced dementia (McPerson et al., 2001) the broader focus presented here has important implications for life story interventions aiming to improve quality of life in such individuals.

The issue of factual information has been raised with respect to life story work in clinical practice, specifically that life story work may focus on the facts that the worker wishes to collect via a life story template rather than the stories that the individual with dementia wishes to tell (Kindell et al., 2014a) or that the format may encourage listing and labelling of information (Spilkin and Bethlehem, 2003). Within the narrative literature, Baldwin (2008) discusses the challenges that people with dementia have faced in getting their stories heard, often arising from the view that they are unable to communicate. Arguing for active maintenance of narrative agency in people with dementia, he stresses the importance of moving beyond a focus on language to consider creativity in expression and joint authorship of narratives, such as the approach of Keady and Williams (2007); this, he argues, involves maximising the opportunities for narrative expression through generating life histories and enhancing communication between people living with dementia and staff. The life story interventions in this study are in keeping with this approach, creatively co-producing a range of individualised products to support transaction and interaction. This study demonstrates the challenges within life story work in semantic dementia and that rigidity in approach is problematic in this client group, particularly as the condition progresses and an individual’s abilities with transaction change. In addition, it could be argued that an exclusive focus on the transactional components in life story work risks rendering people with more advanced semantic dementia, in the terms used by Baldwin (2008), as narratively dispossessed. A
broader focus on making connections from an interactional perspective opens up possibilities to focus on strengths that support the person’s identity and sense of self.

This notion is also in keeping with the work of Hamilton (2008b) in her examination of Elsie’s narratives in the face of advancing Alzheimer’s. Elsie displayed significant difficulties with communicating coherent narratives; however, ‘snapshots’ of the past were evident even within fragmented talk. Hamilton (2008b) argues for the possibility of identity work within the here and now by focussing on instances of formulaic small talk, compliments, jokes and positive politeness (Brown and Levinson, 1987). These are many of the features displayed within Sarah’s interaction in her singing videos and the abilities that Karina attempts to facilitate in Doug in their video data. Moreover, this broader focus on interaction, self and identity may also help some family carers understand recurring topics from the perspective of the person with semantic dementia, a feature I have outlined in the conversation data. The format of the life story books for Peter and Ruby legitimised repetition of the stories they enjoyed telling. In addition, the format also encouraged other stories they currently told less often and enjoyed talking about.

It has to be acknowledged, however, that Ruby’s case highlights some complexity within the impact of life story work on interaction. There were positive aspects to the work in that her talk was more focussed and easier to follow, with a variety of topics and less stories of complaint. However, she told less extended stories and as a result she used less direct reported speech to act out the dialogue. The analysis indicated that the reduction in direct reported speech may have occurred because of a reduction in extended storytelling. It is open to debate about whether this was positive or negative, or indeed, whether the resulting interaction had elements of both poles. Whilst ‘garrulous’ talk has been described in semantic dementia (Kertesz et al., 2010) I could find no literature exploring how to manage this area in daily life. Moreover, the general dementia literature has an almost exclusive focus on encouraging people with dementia to talk (Manthorpe et al., 2015; Ripich et al., 1999; Young et al., 2011), with no discussion of the issues in those who might talk ‘too much’. In my own clinical practice, I have come across this issue in other individuals with semantic dementia. For some family carers this leads to avoidance in starting a conversation in the first place. In other instances, however, it has led to
severe strain in relationships because of carers feeling the person is talking at them, without taking account of their needs and this fuels a feeling of disconnection. I therefore, regard this case study as providing some insight into these challenges and a task for future research would be to explore life story work in other individuals with similar conversation changes.

Lastly, the data here confirms the suggestion that photographs taken during life story activities could be used to illustrate the interest and joy this brought the participants in order to explore outcomes for this work (Kindell et al., 2014a). The study goes further in using video data to examine the in-the-moment effects on participation including recurring features of interaction or differences in terms of interaction during life story work compared to casual conversation and this includes analysis of verbal and embodied behaviour.

**Emotional Connections**: the use of life story work in this way has been described as ‘a psychological process with couples/families to help them positively connect as a couple or family unit, or help them get through a difficult time, e.g. post diagnosis; increasing or changing a care plan. To help the person with dementia connect with their own identity in a positive way and to feel valued and feel that they matter’ (Kindell et al., 2013, p.159). As I have illustrated in the previous chapter, the emotional connections between family members were evident in life story work and this also helped the person with dementia connect with their own identity. The psychological value of reminiscence for older people was first raised by Butler (1963) and some life story approaches in the literature use a process of life review to methodologically work through an individual’s life events in order to re-evaluate and reintegrate past memories as a psychological intervention (Haight et al., 2003). Westerhof et al. (2010) in their review of reminiscence divide approaches into: simple reminiscence that stimulates social aspects and enhances personal well-being; life review that is directed at enhancing aspects of mental health, particularly during times of difficulty or adversity; lastly, life-review therapy that particularly seeks to alleviate depression. They caution that there may be different goals and methods for each and that effectiveness should be studied in relation to the specific goals for intervention. This study generally worked at the level of simple reminiscence to
encourage social aspects and well-being. However, for Ken, the approach was aimed more specifically at enhancing mental health following his diagnosis.

The life story work, whilst enjoyable, also presented emotional challenges for some of the family carers in this study. Ingersoll-Dayton et al. (2013) reported similar issues in their life story work with couples in that whilst most participants reported very positive reactions to the programme, a few were saddened by the losses they had experienced, including memories of things they could no longer do together and a greater recognition of the person with dementia’s memory impairment. Joint reminiscence and sharing of stories in couples’ intervention work was advocated by Wadham et al. (2015) arising from their review to strengthen emotional connections and, therefore, relationships. Whilst this was possible and valuable for Peter and Joanna, and Ruby and Brian, this was not possible for those living with more advanced semantic dementia. For Sarah and Reg, and Doug and Karina, creative ways to make in-the-moment connections were important, illustrating again, that life story work requires greater attention to embodied and sensory dimensions.

I have also discussed the emotional connections for myself; the nature of the work meant people with semantic dementia and/or their family carers revealed details about their lives and I too shared aspects of my own. Sharing of lives has been described as important for breaking down barriers between staff and residents in care settings (McKee et al., 2002). However, this led to a depth of connection and relationship not always present in research or clinical practice and this had to be acknowledged. At times this had the potential to blur the boundaries between research practice and personal lives and, like McKeown et al. (2006), I found supervision was important in setting professional boundaries in this area.

Whilst general quality of life measures have been used to evaluate life story work and reminiscence (Subramaniamay et al., 2014; Woods et al., 2012), the quality of life measure in this study DEMQOL (Smith et al., 2005) was too broad to tap into the specific emotional aspects of the life story work. However, in-the-moment emotional connections could be observed in the video data. This raises an interesting issue in terms of measuring outcomes in this project and many activities in dementia care: making a distinction between in-the-moment outcomes of an activity, i.e.
measuring various aspects of participation and emotional connections and the measurement of other longer term outcomes once the activity has finished.

**Building New Connections:** this theme has been described as ‘as a process to help build supportive relationships and partnerships in care between staff, the person with dementia and their relatives. This includes providing an overt challenge to depersonalised care or practice’ (Kindell et al., 2014a, p.159) and this was evident in data from Peter and Doug. Life story books have been described as useful resources to help get to know an individual when they have moved into a new care environment in both older people (McKeown et al., 2006) and those with a learning disability (Hewitt, 2000). Life story work has a ‘capacity to humanize patients’ for staff in residential settings (McKeown et al., 2006, p.242). This focus on biography is an essential feature of person centred approaches to dementia (Brooker, 2007; Kitwood, 1997a; May et al., 2009) and encourages staff to see beyond the dementia to understand the individual, their history and their identity, therefore, developing a greater understanding and tolerance of current behaviours and shaping person centred attitudes (Clarke et al., 2003).

Whilst his previous life story book helped staff to understand the life Doug had lived, it was limited as a resource for current interaction. In contrast, Doug’s sheet ‘Making Connections’ described ways to connect with him in the here and now. An important aim was to make Doug memorable to staff by focussing on his unique skills in the present and by doing so, shape positive interactions and build new connections. Kitwood (1997b) wrote ‘if I were to choose one issue that marks out good care from bad, the new culture from the old, it would be that of appreciating the uniqueness of persons’ (p.36), arguing for the importance of life history in care practice. However, in my clinical experience people with dementia may sometimes be remembered in care settings for negative reasons arising out of changes in behaviour and this has been described in frontotemporal dementia (Koehn et al., 2011). In his sheet, aspects of Doug’s interaction were succinctly outlined in a positive and memorable way with clear indicators for actions to build new connections, therefore, providing an important starting point to appreciate, as Kitwood (1997b) argues, Doug’s uniqueness.
Kindell et al. (2014a) argue that an important analysis for examining outcomes within building new connections may be through analysis of attitudes and satisfaction with care. As I have discussed, I did not have data to evaluate the life story work in Doug’s care setting, however, Karina was happy with how well Doug had settled at interview and pleased with their interactions with him. One study found that staff attitudes improved following life story interventions with residents (Subramaniamay et al., 2014).

**Practical Care Connections:** The aim of this theme encompasses activities aiming to ‘provide an appropriate care plan and activities for a person with dementia built around their particular needs’ (Kindell et al., 2014, p.159) and this, therefore, represented the more practical aspects of care too in this data set. There is evidence that care plans in long term care may not reveal who the person is behind the plan (Coker, 1998), but that attention to life story work can influence care planning and care practices (Hansebo and Kihlgren, 2000). This can be seen in the present study in how the staff in the day care centre used the life story information to plan appropriate activities for Peter and the care home staff organised Doug’s music for him to listen and conduct along with.

Again, I only have carer reports that the care delivered to Peter and Doug was individualised to their needs, however, auditing care plans for key aspects of life story information as recommended by Kindell et al. (2014a) would appear appropriate for those in this study. Additionally, it could be explored whether information had been translated into practical strategies. For example, whilst the fact that Doug liked to listen to music was interesting information, the actual translation to practice was that his music should be put on regularly in the quiet lounge and he be given two wooden spoons to hold to conduct. It is this latter aspect of life story work that requires further exploration and whilst many resources encourage gathering of information, few explain how this can be used in care (see May et al., 2009, for an exception to this).

Whilst in the original formulation practical care connections were envisaged to be about others caring for the person with dementia (Kindell et al., 2014a), in this study life story work also had capacity to help the person with semantic dementia make
practical changes in their own life, in terms of self-management and this therefore presents as a new finding. In Ken’s case this was done by direct conversations about the condition and a focus on activities to keep him engaged, whilst for Ruby it was possible to use life story work to talk about keeping well and active without necessarily talking about the diagnosis.

**Future Connections:** This is a new theme arising from the data in this study and refers to elements of life story work carried out within the present, but with a consideration of future goals and issues. This presents life story work and resulting resources in a dynamic context that may require adaptation as the person’s needs change. This finding presents as a departure from the life story literature, although this issue has been mentioned in therapy approaches for progressive aphasia. For example, Rogers and Alarcon (1998) argue that interventions for those with primary progressive aphasia should not just focus on the present but include proactive management: ‘therapy goals should be implemented in anticipation of continued decline in communication independence’ (p.645). Whilst to those working in the field of dementia care this may seem obvious, in contrast, the current literature exploring interventions in semantic dementia is largely focussed on present deficits, particularly word retrieval, with no plan for future communication change (Jokel et al., 2014; Savage et al., 2014).

**6.6.5 Life Story Work - Summary of Outcomes**
Life story work in this study had the potential to target a range of goals and, therefore, deliver a range of outcomes unique to each individual with semantic dementia and their family members. Cognitive, psychological and social factors impacted on life story work in terms of assessment, delivery of the intervention and when examining outcomes. A number of authors have highlighted the need to clarify the focus and goals of life story work in order to set more appropriate outcome measures (Kindell et al., 2014a; McKeown et al., 2006; McKeown et al., 2015) and the range of potential outcomes demonstrated within these five cases, confirms the importance of this. So, for example, the aims for Ken were primarily emotional and practical, focussing on improving his current mental health and engagement in activities. Sarah’s therapy, in contrast, aimed to deliver opportunities to improve in-
the-moment interactional and emotional connections with her family. These different goals require different life story approaches and exploration of different outcomes.

6.7 The Role of Intervention – A Summary

Interventions for communication in semantic dementia are dominated by impairment based approaches which aim to improve underlying function. Whilst this may lead to improvements in word retrieval within the experimental design, there is less evidence about the long term effects of such treatment strategies. Croot et al. (2009) discuss the challenges of using such approaches in progressive aphasia (including semantic dementia), in particular the psycho-emotional distress inherent in trying to maintain words in the face of declining abilities. They quote an earlier study, Graham et al. (1999b) where the therapy with ‘DM’ was reported as both helpful and problematic: ‘although this perpetual homework had a beneficial effect on DM’s anomia, it seems to have had the opposite effect on his psychological wellbeing’ (p.377).

In contrast, this study aimed to focus on activities and participation in interaction and facilitate on-going adaption to interaction in semantic dementia in order to enhance well-being. As such therapy was highly individualised to each couple. The data show that ‘being adaptive and flexible’ (Kindell et al., 2014b) was also a relevant underpinning theme for those delivering interventions to people with semantic dementia, in order to deliver intervention that is appropriate to the person, their family carers and the context(s) in which they live. The severity of the language disorder did not always predict the level of difficulties with interaction in the home situation. In keeping with the bio-psycho-social model, how the person reacted to their difficulties and how others facilitated interaction were also key factors (Sabat, 2008). This study, therefore, demonstrates that targeting intervention on the basis of the language disorder alone might not identify those most in need in terms of conversation and well-being at home. This indicates, therefore, that an important part of assessment and intervention is to recognise those individuals and couples who are struggling to adapt to life with semantic dementia, irrespective of the stage of the condition. Warning signs for this from this study might include those couples who appear to be working apart or who display conflicting views about their situation,
where there is overt frustration and conflict within interaction and where carers, or the person with semantic dementia, appears overwhelmed by grief. In terms of communication, therapy might best be offered in the earlier stages of semantic dementia in order to facilitate adaptation and, if possible, prevent maladaptive behaviours becoming entrenched. Intervention could be offered again, if and when, further difficulties arise as the condition progresses or needs change.

Whilst the methods of intervention in this thesis appeared separate, there were overlaps. For example, individualised advice around interaction occurred in all cases, often alongside the life story work and conversation analysis was used to examine the in-the-moment use of life story work. I have called this approach ‘interaction-focussed life story work’ and presented a model in the previous chapter to underpin this work. Moving to consider the interactional benefits of life story work also requires a shift to consider goals and outcomes, beyond reporting the events in a given story, inherent within conversation. Schiffrin (1988) describes conversation ‘as a vehicle through which selves, relationships and situations are talked into being’ (p.272). Conversation thus underpins relationships, with Maynard and Zimmerman (1984) arguing that relationships can be viewed as ‘something that is subject to the on-going step-by-step management within talk rather than a state of affairs that underlies their talk’ (p.302). It is, therefore, within conversation that relationships are created, maintained and performed.

In terms of narrative, storytelling in conversation is not the performance of a monologue but an interactive endeavour and, as in all conversation, a variety of activities beyond reporting facts can be achieved, including joking, arguing, telling troubles, complaining, entertaining, gossiping, justifying, commemorating, conveying pride etc. (Mandelbaum, 2003; Sidnell, 2010). In this way storytelling within interaction allows for identity to be enacted in a variety of ways, in all its complexity.

Taking these arguments together, therefore, it could be suggested that life story work in semantic dementia focussing on interaction, has the power to talk identities and relationships into being; ‘narrative skill can be thought of as an activity to use the sharing or retelling of past experiences for interactional ends’ (Mandelbaum, 2003,
p.601). The goal, therefore, is not just the factual context of the story, as has often been the case within life story work in clinical practice (Kindell et al., 2014a), but the interactional ends achieved within the moment by moment communication. The behaviour of all participants within the encounter is crucial in telling stories in conversation (Jefferson, 1978; Lerner, 1992; Mandelbaum, 2003) and this has been shown to have particular relevance for dementia care (Hydén, 2011; Hydén, 2013; Hydén et al., 2012) and this study confirms this for semantic dementia.

This study has also demonstrated that, even with significant challenges with communication, skills can still be displayed within interaction and these skills can be actively facilitated with life story work. The life story work involved finding out about unique aspects of an individual, including their skills and interests, and using this knowledge to shape shared experiences. The use of audio and video data in this study to explore this was crucial. Goffman (1967) has described how talk can create a 'communion of reciprocally sustained involvement' (p.116) and this can be demonstrated as present within certain interactions in this study, even those involving people with advanced semantic dementia.

There were differences in reaction to the diagnosis for the people with semantic dementia in this study, as has been reported in the general dementia literature (Aminzadehi et al., 2007). Life story work, in contrast to some supportive interventions involving people with dementia, does not hinge on awareness or ability to discuss diagnosis and therefore presents as an intervention that enables a focus on identity, relationships and keeping well generally, rather than a focus on understanding the diagnosis of dementia. In this way, life story work may present as a useful intervention for those who have less awareness or insight, including some individuals with frontotemporal dementia.

6.8 Performance and Representation of Semantic Dementia

After reviewing the interventions delivered in this study I will now return to the issue of adaptation in the person with semantic dementia. In this section I discuss recurring aspects of how stories were told or how experiences were enacted by the person with semantic dementia, to illustrate some of the recurring skills evident in
the participants that displayed aspects of performativity. For example, I have outlined issues of acting out scenes, emotions and accents in talk, as well as singing in both conversation and life story work. These skills can also be viewed in terms of their effect on others, i.e. the audience.

Performance is an area where the data intersect narrative analysis, conversation analysis and elements of performance studies. Schechner (2014) for example, notes that performance studies generally falls into two schools one developed from ‘the intersection of theatre, dance, performance art and the social sciences’ and the other ‘rooted in oral interpretation, communication, speech-act theory and ethnography’ (p.5). The field of performance studies breaks down the divide between what might be perceived as performance and everyday life, thus performance is a ‘broad spectrum or continuum of human actions ranging from ritual, play, sports, popular entertainments, the performing arts and everyday life performances to the enactment of social, professional, gender, race and class roles’ (Schechner, 2013, p.2). This notion is apparent in this data with recurring behaviours from participants that can be viewed and analysed ‘as performance’ (Schechner, 2013, p.168).

The performance observed, in the present, was also often compared with elements of the person with semantic dementia’s past. For example, when observing her current behaviour when singing, Sarah’s family talked about her long standing love of singing and how this was part of her long standing identity. In contrast, Doug’s new found love of music and dancing appeared at odds to his family with his past interests and is positioned as arising from the dementia. There did, however, appear to be greater roots in the past with Doug’s upper class accent with Karina reporting that this behaviour is derived from his mother, going on to tell about the long standing family joke that Doug was ‘posh’.

The interplay between how the present performance is positioned against the past is an important aspect of performance analysis within the field of narrative inquiry (Phoenix et al., 2010; Riessman, 2008) and performance studies (Schechner, 2013). Whilst I have not conducted a performance analysis on the data, not wishing to introduce another method, I have drawn on some of the theory within this area to raise some important overarching questions about the data. Reissman (2008) notes
that stories are produced in a context and as such are co-produced with a story teller and a listener. In some ways, like conversation analysis, performance analysis attempts to unpick some of these elements. Phoenix et al. (2010) argue that performance analysis is an attractive method because it can ‘explicitly illuminate how the researcher shapes and is shaped by the research process’ (p.7). This is an important point because this study was an intervention study and therefore the explicit aim was to shape interactional behaviour. This is most obvious in the interventions with Sarah where the life story work was co-produced by the researcher with the family. The gathering of relevant songs together shaped the performance and I was able to capture some remarkable and touching moments of Sarah and her family, performing together. As the researcher, I then edited this material to use in the final product. The product was then used to help Sarah relive the moment and perform again with her family, with this cycle of performance having important effects on her sense of well-being and identity.

When ‘shaping the performance’ I had to make choices about what to focus on and include. This was not always easy. Sarah had developed a recurring habit, since the onset of her dementia, of kicking and holding her leg high in the air. On one level this was a striking act, however, I knew that her family did not like this behaviour, viewing this clearly as part of the dementia and so I edited all such moments out of the final DVD. In Ruby’s case, I was troubled by the level of negative emotion conveyed at times in her unstructured stories and I could see too that this also made Brian uncomfortable. I, therefore, deliberately made the choice to seek out other positively affirming stories that she could tell and include these in her life story book and I was pleased that the book displayed a more reflective and humorous side to her character.

As I have also discussed, the life story work presented some challenges to family members. Sarah’s performance reminded her family of how she used to be. As Schechner (2013) notes ‘performances mark identities, bend time, reshape and adorn the body and tell stories’ (p.28) and Sarah’s performance, it could be argued, was in some ways an autobiographical performance in the present but also from the past. Her family, as the audience, were aware this was only a moment and not a lasting performance and this also brought them sadness.
Performance analysis also raises some questions about other audiences, as I have ethical approval from some of my participants to show extracts of video in lectures. I have shown video data of Sarah and her family singing to a number of different audiences of researchers and clinicians and, on every occasion, a number of audience members have been brought to tears, so much so that it is good practice to warn the audience that the data may have this effect. In the case of Doug and his use of enactments and his upper class accent, audience members find his skills remarkable and they often laugh, as do Karina and I on the video, at his characterisation. Using the data in this way I am deliberately choosing to show clips that challenge the representation of semantic dementia, and frontotemporal dementia in general, that is evident in the biomedical literature. As I have described in the introduction and literature review, the labels describing the personality changes in people with frontotemporal dementia (e.g. ‘embarrassing’, ‘indifferent’, ‘self-centred’) have been noted to be particularly problematic in frontotemporal dementia with such labels implying not a lack of ability, but implying the individual lacks the moral ability to act correctly (Smith, 2010). As I have outlined, positioning the problem as the person rather than the dementia has been raised as a potential barrier to coping in families living with dementia (La Fontaine and Oyebode, 2014) and this therefore raises the issue of whether the representation of frontotemporal dementia within the literature, in leaflets and on the internet, effectively disentangles the person and the condition.

The other issue facing the representation of semantic dementia, is with respect to ‘curious’ symptoms and the tendency to study these from only the perspective of neuroscience or the problematic nature of such behaviours for carers. The book by Kertesz (2006) ‘The Banana Lady and Other Stories of Curious Behaviour and Speech’ is a good example of this, with the 19 lives in the book described on the book cover as ‘stranger than fiction’ and ‘each selected for the drama and strangeness of behaviour, personality or cognition’. I do not wish to imply that study of the brain is not important, or that such behaviours are not extremely problematic for carers, my argument is that in order to move forward with interventions, we must also study and represent the experience and perspective of the person with semantic dementia and that this in turn is helpful for the carer. Moreover, triangulating this knowledge in a bio-psycho-social frame within interventions helps all concerned.
Balancing the needs of the person with dementia and their family is an underpinning theme within community dementia practice, for example, within the realm of risk, the contested territories of everyday life have been presented by Clarke et al. (2010; 2011). Within this project, I have used conversation analysis to present the interactional territories of everyday life in semantic dementia and, in a similar way, illustrated that understanding the perspectives of all concerned is important for realistic and sensitive management.

In order to help this process, or to provide empathy training as Wray (2014) has advised for carers, it is therefore important to consider how semantic dementia is being represented to those living with the condition and their families by researchers and health and social care professionals; in particular, whether the information, advice and training offered effectively positions the problem with the dementia and not the person. In this respect the representation of semantic dementia may present as a barrier to successful adaptation of the family unit. Accessing useful and understandable information was reported as a problem within four out of the five cases in this research project.

The rise of person centred care (Brooker, 2007; Kitwood, 1997a) and the dementia advocacy movement, currently evident in such organisations such as the Dementia Engagement and Empowerment Project (Mental Health Foundation and Joseph Rowntree Foundation, 2014) has challenged practice to move away from the carer centred models of the past to a more balanced view. However, the participation and representation of people with frontotemporal dementia within the area of advocacy is minimal, in part arising from challenges with insight and communication difficulties. In this study, however, Ken showed good insight into his situation and he displayed evidence of self-management of his symptoms with insightful descriptions that would be helpful to others living with early semantic dementia. Another option to achieve balance may be to use creative ways to represent and understand the experiences of people with semantic dementia, as video has shown in this study. Following on from this, as has been done in the general field of dementia, written information could move away from a focus on the brain and diagnostic terms to a description of the lived experience and how behaviours can be presented as arising
from the condition (not the person), with a greater focus on meeting psychological and social needs.

In summary then, consideration of performance engages more creatively with the skills that may be present in the person with semantic dementia and the effects this has on the localised audience and, in this study, potentially other audiences. This knowledge can be used as an important part of life story work. In addition, using this knowledge may help to foster a more balanced representation of semantic dementia.

6.9 The Potential of Music

I have discussed the love of music participants expressed in this study and how this was used for some within the intervention. Music is discussed within the dementia care literature in a variety of ways with a range of reported benefits but also with challenges in defining and examining outcomes (Cameron and Sosinowicz, 2014; McDermott et al., 2013). Music therapy, often delivered in groups in care settings, has been shown to produce short-term improvements in mood and a reduction in behavioural disturbance (McDermott et al., 2013; Raglio et al., 2010; Sung et al., 2012). Other studies have explored the potential of joint music sessions to improve relationships with staff (Götell et al., 2000) and with family carers (Brotons and Marti, 2003; Clair and Ebberts, 1997). However, long term benefits have been particularly difficult to evidence (Livingston et al., 2005; McDermott et al., 2013) with a recent Cochrane Review reporting that ‘there is no substantial evidence to support nor discourage the use of music therapy in the care of older people with dementia’ (Vink et al., 2011). One of the obvious issues is how to define studies examining music as music therapy or music as activity (McDermott et al., 2013) or indeed music for pleasure; the latter being close to the place of music in many of our lives. Singing together appears to be the activity most easily translated into everyday practice and this includes the popular ‘Singing for the Brain’ groups run by the Alzheimer’s Society (Osman et al., 2014).

The literature, as noted in the introduction, has explored skills with music in frontotemporal dementia (Hailstone et al., 2009; Miller et al., 2000; Warren et al., 2011; Weinstein et al., 2011) with a heightened liking for music, described as
‘musicophilia’, noted to be particularly common in frontotemporal dementia (Fletcher et al., 2015; Fletcher et al., 2013). There are a number of reports of this, with exploration of this behaviour for implications for diagnosis or broader studies of the neurobiology of music within the human brain (Boeve and Geda, 2001; Hailstone et al., 2009; Miller et al., 2000; Weinstein et al., 2011). In some reports excessive listening to music has been displayed as a problematic behaviour (Boeve and Geda, 2001). The semantic dementia literature lacks any detailed exploration of the benefits of music from the perspective of the person with semantic dementia or their family. This study, however, demonstrates the positive effect of music on well-being for Sarah and Doug and particularly in Sarah’s case that the singing of familiar tunes can be used as a vehicle to improve interaction in the home situation with family members. Sarah’s case illustrates the effects on interaction in detail and the positive benefit this has to Sarah in affirming her identity. Moreover, the case demonstrates that music facilitates a different range of skills than everyday conversation and evidences the reports in interviews that music has a special effect on well-being. Interestingly the playful and creative effect singing has on Sarah can be observed. The embellishments and over-singing in the data are similar to the embellishments noted in the harpsichord playing in another case study in semantic dementia (Weinstein et al., 2011) with such behaviours indicating that these musical skills are not merely being retrieved whole from long term memory.

Hailstone et al. (2009) argue that the relative sparing of musical knowledge may contribute to musicophilia in people with frontotemporal dementia therefore raising the issue that this behaviour is underpinned by the retention of skills. This raises an interesting point in that this might, therefore, be another adaptive response, where the person uses the skills they have at their disposal to engage in activities that provide them with pleasure. Sarah’s case study illustrates that interventions may be able to build on this adaptation by providing appropriate opportunities that are shared with family members, contributing to interactional and emotional connections.

6.10 Methodological Innovation

In order to evaluate the life story music DVD in Sarah’s case I examined whether literature beyond the field of interaction would inform the analysis including: music
therapy, dance and performance studies. Examining the field of performance studies, I was unable to find a framework that adequately analysed the finer detail of the data, particularly issues of moment by moment interaction, but the field did pose some important overarching questions and ideas to explore within the data, as I have just highlighted with respect to narrative and performance. Exploring the music therapy in dementia literature led me to the ‘Music in Dementia Assessment Scales’ (McDermott et al., 2014). However, again I found this tool lacked the ability to analyse the unique aspects of performance and interaction within the quantification of engagement. Sarah presented as top of each visual analogue scale in interest, response, initiation, involvement and enjoyment, with the scale, rather surprisingly, lacking any particular detailed exploration of reaction to music. Some projects examining singing had used interviews to explore experience (Osman et al., 2014) but this would not have been appropriate for Sarah because she did not have the cognitive ability to reflect on the experience, even shortly after the event.

The collection of detailed approaches outlined within Wosch and Wigram (2007b), however, illustrated a range of micro analytical approaches to music therapy with similar aims to my own. In their introduction, Wosch and Wigram (2007a) discuss whether outcomes for music therapy are examined following a course of music therapy, following a session, within a session or even within events or moments within that session. In their overview of methods they outline that ‘therapy events’ might represent musical, verbal or nonverbal phrases, for example, part of a song occurring within the music therapy session. This in turn can be broken down into ‘moment-by-moment experienced change’ (p.22) lasting even just a few seconds, where a change at this smallest level can be observed. Whereas some of the micro analytical approaches outlined examine music making with musical instruments, others, in particular the work of Ridder and colleagues (Ridder, 2007; Ridder and David Aldridge, 2005; Ridder et al., 2009), examined the use of song in music therapy sessions and a system of analysis using video data that overlapped, in some respects, to the stance taken in conversation analysis. I decided to use the following elements to explore the in-the-moment experience in detail:

- The principles of conversation analysis whereby the video is viewed in entirety with interesting recurring features noted.
• Collections were then made of these recurring features using transcriptions of the data including speaking and singing and these were subjected to further detailed analysis.

• Transcription of relevant body movements was also included and photographs were added to further display embodied aspects (particularly where description of parts of the scene would not convey the whole scene).

• Questions from performance analysis examining effects on the audience and embodied singing performance were used to further explore the data.

I used this as a data driven method to analyse recurring features in the singing data. This moved the analysis from one examining in-the-moment issues as separate sequences (Wosch and Wigram, 2007a) to one that examines recurring patterns or ‘recurring moments’ in the data. In addition, this allowed for a qualitative comparison between the recurring moments during conversation and those during singing. In this analysis I took the principle from interaction-focussed therapy that there are different choices for participants within situated interaction and ways to draw on different resources (Wilkinson, 2010; Wilkinson, 2015) and by using this, I hoped to move away from notions of ‘which is better’, to an in-depth analysis of what the different situations potentially can bring in terms of choices within interaction.

This method took the open stance of conversation analysis, whereby anything within the data was potentially of interest, rather than resting on a system of predefined codes that may miss certain behaviours as evidenced in McDermott et al. (2014). In addition, behaviour was studied in context and not pre-coded by the researcher as positive or negative, the focus was on how participants interacted and behaved at the time, i.e. their contextualised perspective was taken. This open system is similar to that used by Ridder (2007) to study video clips of music therapy, where open description of ‘meaningful events’ (p.60) occur, followed by interpretation and reflections about musical responses using a spread sheet and tabular format. In the method used by Ridder (2007) there is a greater focus on the person with dementia, rather than on both parties within the event, whereas in the method I have used, in keeping with conversation analysis, there is equal focus on both participants within
the singing interaction and, therefore, greater detail of the sequencing within the interaction. In addition, I have also transcribed the song lyrics as though this is a third participant present, enabling precise reaction to, and not just singing of words, to be noted.

One of the challenges for all fields is the ability to convey the results of the analysis to others in an understandable manner, including to those who may be from a different discipline or indeed to a lay audience, without losing the detail or the integration of the whole experience. For example, translating the dynamic processes inherent in Sarah’s video data into text, for this thesis or other publication, threatens to lose some of the complexity of experience contained within the interactional, musical and emotional dynamics inherent in the data. With this in mind, rather than writing a purely descriptive report I have, therefore, taken another principle from conversation analysis as described by Ten Have (2007) ‘it is essential that a conversation analysis paper contains representations of the relevant data, most often in the form of transcribed fragments’ (p.221). By doing this I use extracts of the data, carefully chosen for their contribution to arguments examining the resources displayed within the localised interaction. I have also included photographic material embedded within the text. I have done this because whilst body movements and facial expressions can be conveyed in the text, the sum of the parts did not display the integration, and particularly the emotion, of the whole. In this respect I hope to display the more performative and embodied aspects using photographs. As I am not a musician, my analysis lacks depth within the exploration of features of rhythm and pitch and other musical dimensions inherent in analyses conducted by a trained musician or music therapist (Ridder, 2007; Wosch and Wigram, 2007a). Analysis of this nature might unravel some of the skills Sarah displays within the area I have termed ‘embellishments and over-singing’.

The method I have used does allow for individualised exploration of outcomes and this is a common issue for clinical practice. For example, within a singing group in a care home, a common goal may be to sing along, however, individual participants may have more individualised goals within the task. For one, sitting and not walking for any duration may be remarkable, whilst for another getting up and dancing may be a desirable change. In terms of semantic dementia, it could be that for some,
where there is a lack of conversation, engaging in more active verbal and nonverbal interaction is important, whereas for others, who are overly talkative, listening and engaging in more shared interaction, could be the goal for enhanced connections. As in conversation analysis, there is also the possibility of quantifying individual practices within the data, after the generation of individualised coding, as was conducted in case study one in this thesis or the level of enactment in Doug’s earlier data (Kindell et al., 2013).

In Chapter 3, the International Classification of Functioning, Disability and Health Framework (ICF) (WHO, 2001) was presented including outlining that interventions may target various areas in semantic dementia including brain structures and functions as well as activities and participation in life situations. It can be seen that the life story work with Sarah aimed to foster participation in interaction, through manipulating opportunities in the environment, rather than make changes to function. It could, therefore, be argued that if participation is the primary goal, then evaluating this very participation must be the relevant outcome measure; demonstrated here with in-the-moment changes in interaction. Changes in behaviour and brain functions after the activity has finished, whilst welcome, are secondary. In addition, separating out these aspects is important. Once the music has stopped Sarah returns to complaints about her headache; however, this lack of generalisation should not detract from the in-the-moment effects on interaction and emotion evident in the data and displaying her enhanced participation. Thompson (2009) notes that in the search for the ‘effects’ of performance in terms of social utility, applied theatre is in danger of forgetting the ‘affect’ of performance and I would argue that this is a problem faced too by dementia care. It can be extremely difficult to engage individuals with advanced dementia in activity, however, the achievement and creativity seen within such in-the-moment exchanges can be too easily forgotten when a lack of ‘effect’ in the long term is noted. Goffman (1967) describes these human connections: ‘it is this spark, not the more obvious kinds of love that lights up the world’ (p.117) and I would argue that dementia care would benefit from greater attention to such moments.
6.11 Reflexivity

I now return to an important area within this project, that of my place as a practitioner-researcher. As I outlined in chapter 3, Reed and Proctor (1995) discuss the particular challenges and benefits of carrying out research in this manner and the temptation, particularly within traditional research designs, to ignore or bury such issues. Considering this dual role as both a practitioner and researcher is an important part of reflexivity (Reed and Proctor, 1995). Such issues were on-going throughout this project and an important topic within supervision, for example, reflecting on whether potential tasks were within the remit of the research or could drift into clinical practice beyond the parameters of the project.

As I have discussed my prior experience of working with people with semantic dementia, and dementia in general, was useful at times. This sensitising experience could be used as a resource, for example, establishing rapport and identifying common issue in this client group. I often asked myself if a particular behaviour had important clinical consequences and whether a particular issue, idea or approach to intervention would be useful to my colleagues in the NHS. However, I also had to be careful that my prior experience did not limit my field of vision in terms of data analysis or approaches to therapy, for example, being careful to be open to new possibilities within data analysis or ways of working within intervention. On a practical level, I would examine data more than once and in the case of interactional data on numerous occasions to explore potential issues and study examples of conversation behaviour in depth.

Interestingly, I found it more challenging to work with participants who were not recruited from my own NHS service. This was because in other areas there was a lack of clear provision for younger people with dementia or for those with rarer dementias, leading to low levels of support. Working in a research capacity with individuals that needed more support from health and social care tested both the ethical approval of the project but also my personal ethics as a practitioner. Discovery of unmet need and subsequent referral to appropriate services had been agreed within the original ethical approval and this allowed me to step outside the concrete research tasks and signpost individuals to the help they needed.
It is worth noting that my stance, in both research and practice, aims to be person-centred and place the person with dementia at the centre of intervention, along with those individuals important to them, most often their family. As I have discussed in both chapter two and within this chapter, tensions may exist between the needs of the person with dementia and their family carers. I found that conversation analysis was a useful tool to explore such in the moment perspectives within interaction and moreover this placed equal weight on the experience of both participants. The literature review in chapter two, however, noted that this kind of analysis has yet to be fully exploited in research practice and this, therefore, has important implications for future research.

6.12 Limitations of this Study

The mixed methods approach of this study presents as both a strength and a limitation. Whilst the data was rich and detailed, time constraints meant that it was challenging to deliver an appropriate level of detail within analysis of both data strands, as well as deliver the intervention and analyse the associated outcomes. In particular, there are many other features within the conversation data gathered for this study that could be analysed at a later date. For example, stories can be told differently within two party conversations as opposed to three party conversations (Lerner, 1992) and the data could be subjected to further analysis to explore this area. Another area was ‘banter’ within conversation and this was an important part of interaction for both Sarah and Reg, and Ruby and Brian. Thus, teasing was something both husbands did to draw a reaction from their wives and appeared to be part of an established relationship pattern. This is the nature of working with conversation data, whereby video or audio data can be examined from multiple perspectives and it is common in the field of conversation analysis for data from a particular study to be examined for other conversational features at a later date. This is why the notion of secondary analysis does not fit with a conversation analytical approach.

It was disappointing that the interaction-focussed therapy was only delivered to one couple and further research is required to examine if this challenge is particular to this study, semantic dementia or dementia in general. The insights from this study
may be useful to others designing such interventions. The reluctance of individuals to be video recorded, especially without the researcher present, may mean that those who are struggling to adapt to interaction in dementia might be less likely to volunteer for research studies using video data. There is then a concern that recruitment will be biased towards a more positive view of interaction in dementia, rather than representing a breadth of experience.

In this study I did not assess the use of the life story products by family carers with the person with dementia without the researcher present and this presents as a limitation. Again, use of video without the researcher present would have explored this further, along with assessing the influence of the researcher to the situation. Exploration of outcome measures from the perspective of the person with semantic dementia and the family carer require further study generally. The CAPPCI (Perkins et al., 1997) was very time consuming and repetitive in delivery and although this was used with Joanna to report on Peter’s conversation after therapy there were some issues with the tool. For example, there was some confusion about the terminology when delivering ‘problem’ ratings in that behaviour could still exist as a recurring problem in conversation, but the carer might not rate this highly as a problem to them and the tool did not effectively disentangle this. Further exploration of carer reports of the presence of behaviours, understanding of these and tolerance of such communication features would be useful research of direct relevance for clinical outcome measures.

The participants in this study displayed a range of socio-economic circumstances and levels of education, however, in terms of ethnicity, all participants reported themselves as white British and so the study lacks an exploration in other ethnic groups and cultural contexts.

The present study predominantly focussed on interaction between spouses and whilst other family members were involved in the life story work in the first two case studies, greater exploration of the interactions and experiences of other family members could have brought important additional insights into life with semantic dementia. In addition, the study focussed on interaction in the home setting and as Peter and Doug’s cases illustrated, the inclusion of other important relationships for
life story work (in day care and residential care) would have been useful and these were not systematically addressed in this study.

Lastly, the organic and individualised nature of the interventions was responsive to individual need but presents certain challenges in terms of generalisation to clinical practice and research. The model for interaction-focussed life story work goes some way to draw together the findings in an exploratory model but will require further research to refine and take forward.

6.13 Summary and Conclusions
This study has demonstrated that attention to interaction and life story issues within the everyday lives of people with semantic dementia and their family carers is a fruitful line of enquiry for research and practice. A range of interactional needs and issues were presented in the five case studies here, indicating the complexities of daily life with semantic dementia for all concerned. This also illustrates the challenges inherent in community dementia practice for clinicians working with this client group and that creativity and skill are required to meet these needs. To summarise I now present the outcomes generated from this project in terms of practice, research, policy and education. Appendix 16 contains a summary of publications and presentations disseminating the findings from this study.

6.13.1 Summary of Outcomes for Practice
- This study demonstrated that conversation challenges at home cannot be solely predicted by performance within test situations and assessment of natural conversation at home is also required for effective intervention because individuals with semantic dementia and their family carers demonstrate differences in their adaptation to the condition.
- Family carers used a variety of conversational practices to support the person with semantic dementia including: provision of visual support and enriching the message with additional detail to support understanding, as well as a practice of giving information, followed by a tag question, to circumvent memory problems and draw the person into the conversation.
Test questions used by family carers had different functions and different outcomes depending on the context and the particular interactional needs of the individuals concerned and so examining their use in-situ is required for effective advice within this area.

The study showed that there is potential to use interaction-focussed therapy with people with semantic dementia. However, video may not appeal to some individuals, particularly where couples are required to video themselves without the researcher present and a flexible format may be required.

Individually tailored life story work to enhance interaction was an enjoyable intervention for the people with semantic dementia in this study and this work is transferrable to practice.

Aspects of interaction-focussed therapy and life story work could be weaved together to deliver interaction-focussed life story work.

Examining video and audio data and/or using detailed knowledge of interaction was a key part of assessment and planning within interaction-focussed life story work, rather than a sole focus on gathering factual aspects of life story information or photographic material. An important part of this work was to begin with abilities of the person with semantic dementia within interaction and build from there. For example, the topics and stories the person with semantic dementia likes to talk about, or the activities they currently find enjoyable.

Interaction-focussed life story work needs to foster and value embodied and emotional connections, as well as verbal connections.

Interaction-focussed life story work brings a person centred focus to semantic dementia, in an intervention that can potentially involve the person with semantic dementia, their family and others.

Interaction-focussed life story work should be viewed within a bio-psycho-social frame, with cognitive, psychological and social factors impacting on the work with creativity in format required to meet individual needs with interaction.

Interaction-focussed life story work moves features such as ‘repetitive topics’ ‘garrulous talk’, ‘musicophilia’ etc. from being seen as ‘problem behaviour’ to examining such features from the perspective of the person with dementia.
and allows the reframing of such behaviours in a needs based approach that considers both transaction and interaction. An important aspect to this work is to consider well-being and affect within interaction and not just focus on information content.

- Interaction-focussed life story work is a dynamic on-going process and approaches and formats may need to be adapted as the person’s needs change.

### 6.13.2 Summary of Outcomes for Research

- There is potential for video to be used to explore outcomes of life story interventions as part of in-the-moment analysis of participation in interaction, using conversation analysis. Such an approach could bring a necessary critical exploration of life story work in all types of dementia.
- This approach could also be used to explore participation in a range of activities to examine the opportunities and choices different activities deliver.
- Longitudinal studies exploring adaptation, interaction and life story work in semantic dementia would be useful to give a broader understanding of this condition.
- Pairing narrative analysis and conversation analysis allows for triangulation of data strands giving a rich understanding of both interaction and the lived experience of semantic dementia and this could be used to explore experience and relationships in other dementias.
- The fine detail of the interaction between semantic memory and autobiographical memory in semantic dementia would benefit from further case study research using real world data, due to the inherently unique nature of autobiography; thus effectively bridging the divide between psycholinguistic approaches and social approaches in this condition. This study indicates that the study of cognition in context in semantic dementia appears fruitful, particularly with respect to the stories and performances generated by the person with semantic dementia in naturalistic settings. Multidisciplinary research partnerships to foster such work would enhance knowledge in this field.
6.13.3 Summary of Outcomes for Education

- Placing semantic dementia into a bio-psycho-social frame and moving away from a predominant focus on biomedical aspects within education is important in order for health and social care professionals to effectively support people with this condition in the community.

- There is potential for education initiatives to raise the profile of the needs of people with semantic dementia and their families and the findings of this thesis could contribute to this.

- The importance of moving beyond issues of transaction to consider interactional skills has been demonstrated in this thesis. Initiatives to improve education around communication in semantic dementia should encompass both of these perspectives.

- This study has shown that in life story work in semantic dementia practitioners need to be responsive to individual need and circumstance. It is, therefore, crucially important that life story training includes critical reflection about the life story process, products, goals and outcomes and avoids a ‘one-size fits all’ approach to practice.

6.13.4 Summary of Outcomes for Policy

- Within services across Greater Manchester there was significant variability in understanding of this condition, diagnosis and the services offered to this client group and this requires attention.

- Service commissioners and providers should consider if their services are responsive to the needs of those with semantic dementia and their family members and if interventions are effectively tailored to individual need.

- The representation of semantic dementia and frontotemporal dementia in general, is an area that requires consideration in policy.

- Access to material that represents the experience of the person with semantic dementia in terms that are less morally laden would be beneficial for those living with the condition, family carers and health and social care practitioners.

- This study showed that much of the information material about semantic dementia currently available is written for family carers and there is an urgent
need for appropriate and accessible information for those living with early semantic dementia.

6.14 Concluding Remarks
This study demonstrates that there is much to learn from the situated interactional experiences of people living with semantic dementia and their family members. Narrative analysis and conversation analysis have proved ideal tools to explore this area, with this thesis presenting as an early attempt to combine these approaches. Interaction-focussed therapy can be delivered in semantic dementia but further research is required to explore this. Life story work presents with the flexibility to explore and deliver individually tailored interventions in semantic dementia and other types of frontotemporal dementia. An approach that explicitly considers interaction, interaction-focussed life story work, offers potential to enhance communication at home in semantic dementia and presents as an intervention that could be delivered in clinical practice. Whilst life story work is currently popular in dementia care, close attention is required to adapt methods and practices to individual need, including those with semantic dementia.
References


Keady, J., Williams, S. & Hughes-Roberts, J. (2007) 'Making mistakes' using co-constructed inquiry to illuminate meaning and relationships in the early
adjustment to Alzheimer's disease - a single case study approach. *Dementia*, 6, 343-64.


Lambon Ralph, M. A., McClelland, J. L., Patterson, K., Galton, C. J. & Hodges, J. (2001) No right to speak? The relationship between object naming and


McKeown, J. (2011) *It Made me see him in a Different Light.* The Use of Life Story Work with Older People who have Dementia in Health and Social Care Practice. PhD, University of Sheffield.


Snowden, J. (2015a) Dissociated word production and comprehension in semantic dementia. *Cortex*, Published online ahead of print.


Wray, A. (2010) ‘We’ve had a wonderful, wonderful thing’: Formulaic interaction when an expert has dementia. Dementia, 9, 517-534.


# APPENDIX 1

## Key to Transcription Symbols

<table>
<thead>
<tr>
<th>Symbols</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>[</td>
<td>A large left-hand bracket links overlapping utterances or non-verbal actions at the point where the overlap begins.</td>
</tr>
<tr>
<td>]</td>
<td>A large right-hand bracket marks where overlapping utterances/simultaneous non-verbal actions stop overlapping.</td>
</tr>
<tr>
<td>e.g.</td>
<td>01 PR how have you been since I last saw [you] [not] so good</td>
</tr>
<tr>
<td></td>
<td>= An equals sign marks there is no interval between adjacent utterances.</td>
</tr>
<tr>
<td>e.g.</td>
<td>01 DG did he really say that?= 02 FB =yes</td>
</tr>
<tr>
<td>(0.6)</td>
<td>Silences are marked in seconds and tenths of seconds, i.e. (0.6) is six tenths of a second; (1.2) is one second and two tenths of a second.</td>
</tr>
<tr>
<td>( . )</td>
<td>A full stop in single brackets indicates an interval of tenth of a second or less in the stream of talk.</td>
</tr>
<tr>
<td>oh:</td>
<td>A colon indicates an extension of the sound or syllable it follows (more cols prolong the stretch).</td>
</tr>
<tr>
<td>but-</td>
<td>A single dash indicates an abrupt cut off to a word or part of a word</td>
</tr>
<tr>
<td>↑↓</td>
<td>Marked rising and falling shifts in intonation are indicated by upward and downward pointing arrows immediately prior to the rise or fall.</td>
</tr>
<tr>
<td>stress</td>
<td>Underlining indicates emphasis.</td>
</tr>
<tr>
<td>°no°</td>
<td>Degree signs indicate talk which is quieter than surrounding talk.</td>
</tr>
<tr>
<td>TALK</td>
<td>Capital letters indicate talk at a louder volume than surrounding talk.</td>
</tr>
<tr>
<td>hhh</td>
<td>Indicates discernible aspiration or laughter.</td>
</tr>
<tr>
<td>((nods))</td>
<td>Double brackets represent a gloss or description of some non-verbal aspect of the talk</td>
</tr>
<tr>
<td>(1 syllable)</td>
<td>A word, phrase, or syllable count (if utterance is very unclear) mark where target item(s) is/are in doubt to the transcriber.</td>
</tr>
</tbody>
</table>
APPENDIX 2

Literature Review Examples of Extraction Tables

Three tables, giving two examples in each are presented from each of the following areas to illustrate how extraction tables were used within the literature review:

Table A2.1 - Conversation in Alzheimer’s disease, vascular dementia and Lewy body dementia.

Table A2.2 - Co-constructed conversational storytelling.

Table A2.3 - Conversation in frontotemporal dementia and primary progressive aphasia.
Table A2.1 Conversation in Alzheimer’s Disease, Vascular Dementia and Lewy Body Dementia

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Longitudinal conversations recorded over 4.5 years with ‘Elsie’, a woman with Alzheimer’s and Hamilton, recorded in care home. At the start Elsie had moderately severe cognitive decline (as per GDS score 5) and by end very severe cognitive decline (GDS 7). Approval noted.</td>
</tr>
<tr>
<td>Participants</td>
<td>In-depth changes in communication over time using conversation analysis, large data set, numerous examples. Qualitative and quantitative data. Skills even late in the condition, e.g. use of minimal turns to maintain turn-taking, indicating recognising important topics. Self-repair declined – Elsie attempted less and seemed less aware of need to repair.</td>
</tr>
<tr>
<td>Recruitment strategy</td>
<td>Demonstrated the importance of analysing natural conversation to demonstrate skills and difficulties and part played by conversation partner. Elsie had increasing problems viewing the role and likely thoughts of the other person. Hamilton had to take on increasing responsibility to sustain and direct conversation.</td>
</tr>
<tr>
<td>Data collection</td>
<td>How valuable is the research to practice?</td>
</tr>
<tr>
<td>Ethical issues</td>
<td>Reviewers notes</td>
</tr>
<tr>
<td>Analytical method</td>
<td>One of the earliest conversation analysis studies, findings widely cited. High quality in-depth analysis and data.</td>
</tr>
<tr>
<td>Findings/outcome</td>
<td>Looking at communication during care activity – taking a shower. Notes data gathered through observation and audio and visual recording. Adapted conversation analysis</td>
</tr>
<tr>
<td>Participants</td>
<td>Data taken from a larger study looking at communication during care work in three care homes using variety of methods. Three women with ‘intermediate stage’ dementia and three assistant nurses two female and one male. Recorded in care</td>
</tr>
<tr>
<td>Recruitment strategy</td>
<td></td>
</tr>
</tbody>
</table>
**Ethical issues.**

| Home at shower time. Ethics – study approved by regional ethics committee and residents and relative ‘informed by letter’, researcher cautious and alert for any signs of resident’s unwillingness to be observed or recorded. |

<table>
<thead>
<tr>
<th><strong>Analytical method</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Use adapted conversation analysis together with sociolinguistic theory of politeness. Two hours of data transcribed and analysed for this paper. In-depth analysis with 11 extracts of conversation presented. All three residents protest that they do not want to have their hair washed, but two of the care workers are able to engage in this task – evidenced through their communication - in a less confrontational manner that takes account of what the residents are feeling, and saying, at the time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Conclusions drawn</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Illustrates the skill within this kind of work by the care workers involved – particularly the skill in keeping residents calmer and less distressed; skilled workers able to negotiate the activity with the resident. Things particularly break down when carer moves straight to a task orientated manner positioning the resident as helpless with use of ‘elder-speak.’ More successful interactions did not take any longer.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Reviewers notes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Shows important skills in what is regarded as ‘simple labour.’ Complex ethical issues in this study. System of approval very different in Sweden to the UK.</td>
</tr>
</tbody>
</table>

**Depth and n° examples**

**Findings/outcome**

**Use adapted conversation analysis together with sociolinguistic theory of politeness. Two hours of data transcribed and analysed for this paper. In-depth analysis with 11 extracts of conversation presented.** All three residents protest that they do not want to have their hair washed, but two of the care workers are able to engage in this task – evidenced through their communication - in a less confrontational manner that takes account of what the residents are feeling, and saying, at the time.

**Conclusions drawn**

**How valuable is the research to practice?**

Illustrates the skill within this kind of work by the care workers involved – particularly the skill in keeping residents calmer and less distressed; skilled workers able to negotiate the activity with the resident. Things particularly break down when carer moves straight to a task orientated manner positioning the resident as helpless with use of ‘elder-speak.’ More successful interactions did not take any longer.

**Reviewers notes**

Shows important skills in what is regarded as ‘simple labour.’ Complex ethical issues in this study. System of approval very different in Sweden to the UK.
Table A2.2 - Co-constructed conversational storytelling

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspect of conversation examined</td>
<td>Reworking of earlier data, but appropriate selection as aiming to explore identity and narrative in those with later stage Alzheimer’s disease. Audio data of conversations in the care home.</td>
</tr>
<tr>
<td>Design</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>Examining ‘Elsie’ who has significant dementia. See entry in previous table for more details on Elsie and ethical issues in study.</td>
</tr>
<tr>
<td>Recruitment strategy</td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td></td>
</tr>
<tr>
<td>Ethical issues</td>
<td></td>
</tr>
<tr>
<td>Analytical method</td>
<td>Examines five conversations (2 hours 39 minutes). Qualitative &amp; quantitative analysis, conversation analysis and linguistic analysis. 73% of the 204 clauses that referred to the past in the form of ‘narrative traces’ only 27% were part of narratives. Elsie’s has difficulty creating important aspects of the story world, e.g. who, what, when and where etc. Important ‘anchors’ of story world missing. Instead the listener has to attempt to generate clues or snapshots from the narrative traces.</td>
</tr>
<tr>
<td>Depth and n° examples</td>
<td></td>
</tr>
<tr>
<td>Findings/outcome</td>
<td></td>
</tr>
<tr>
<td>Conclusions drawn</td>
<td>Valuable longitudinal perspective and with a person with later stage dementia. Whilst a listener might not be sure what is being communicated on a semantic level they may use cues in the talk to get what they can from narrative traces and thus aspects of identity can come through.</td>
</tr>
<tr>
<td>How valuable is the research to practice?</td>
<td></td>
</tr>
<tr>
<td>Reviewers notes</td>
<td>Narrative traces – fragments of the past is an important idea for those with more advanced dementia. Data looking at narrative in an individual with advanced dementia, later in dementia than most people described in the literature currently.</td>
</tr>
<tr>
<td>Aspect of conversation examined</td>
<td>A discussion paper – using an extract of conversation to illustrate points. Conversational storytelling &amp; in particular observation of embodied dimensions in individuals with dementia. Video data.</td>
</tr>
<tr>
<td>Design</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>Data presented is part of a bigger project – referred to alternative publication where this can be found, therefore broader issues of data collection, recruitment and ethics not discussed here. 1) Oswald (with dementia) and wife Linda recorded at home</td>
</tr>
<tr>
<td>Recruitment strategy</td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td></td>
</tr>
<tr>
<td>Ethical issues</td>
<td></td>
</tr>
</tbody>
</table>
2) Martha and Catherine with dementia in care home

<table>
<thead>
<tr>
<th>Analytical method. Depth and n° examples Findings/outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two examples presented:</td>
</tr>
<tr>
<td>1) One of a couple where husband has dementia, Oswald uses gesture to convey his point and to take part.</td>
</tr>
<tr>
<td>2) Another with two women with dementia, one woman uses direct reported speech with her own dialogue from past, with changes in intonation, body positioning and eye contact along with touch to indicate important aspects of the story.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conclusions drawn How valuable is the research to practice?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argues that storytelling is collaborative and that attention needs to be paid to embodied aspects.</td>
</tr>
<tr>
<td>Argues need to use video for this kind of research.</td>
</tr>
<tr>
<td>Need to pay attention to embodied behaviour but practice applications implicit.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reviewers notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oswald also uses speech along with gesture, not either/or so the combination important.</td>
</tr>
<tr>
<td>Does not address if these are recurring practices, two examples from different participants.</td>
</tr>
<tr>
<td>Family conversations at home – but with researcher present.</td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Aspect of conversation examined?</strong></td>
</tr>
<tr>
<td><strong>Design</strong></td>
</tr>
</tbody>
</table>
| **Participants** | Detailed method using conversation analysis. Extensive analysis and examples provided – 12 extracts. Findings clear:  
- Directives  
- ‘Let’s/we framed’  
- Initiation-response-evaluation  
These sequences resembled parent-child interactions – aimed to affect and guide person with frontotemporal dementia, in some instances was not warranted, i.e. person with dementia had more ability than recognized. |
<p>| <strong>Recruitment strategy</strong> | In this study people with frontotemporal dementia socially constructed as ‘child like’ and this is apparent in the interactions others use towards them. Useful information to illustrate small ways such issues become apparent. |
| <strong>Data collection</strong> | Limitation is that only two of extracts involved family, others involved researchers or paid carers, not conclusive this is how family treat person. |
| <strong>Aspect of conversation examined?</strong> | Examining perseverative behaviours in conversation, caregiver’s responses and how this might contribute to stress. Design appropriate. Conversation analysis. Video data. |
| <strong>Design</strong> | A collaboration between social science and neurology but does not say how/why this person ‘Kelly’ recruited. Diagnosis ‘semantic dementia and frontotemporal dementia’ but presented as person with behavioural variant |</p>
<table>
<thead>
<tr>
<th>Ethical issues</th>
<th>frontotemporal dementia. 7 hours interaction 5 hours of interviews.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Analytical method</strong>&lt;br&gt;Depth and n° examples&lt;br&gt;Findings/outcome</td>
<td>Detailed case study using conversation analysis. Clear statement of findings: carers used: 1) Reasoning or explaining a more appropriate behaviour, 2) Distraction and 3) Physical guidance. 11 extracts provided. Interlocutors treat Kelly’s turns at talk as relevant; they do not for, e.g. dismiss or not respond to what she is saying.</td>
</tr>
<tr>
<td><strong>Conclusions drawn</strong>&lt;br&gt;How valuable is the research to practice?</td>
<td>Carers use a variety of strategies and in this study carers make numerous efforts to address the person’s turn or integrate it into the flow of conversation, despite such perseverative behaviours interrupting the progressivity of the conversation.</td>
</tr>
<tr>
<td>Reviewers notes</td>
<td>Semantic dementia described as ‘not particularly problematic in interaction’. The focus is on the frontotemporal dementia type behaviours. Interactions of family carers versus staff not separated out.</td>
</tr>
</tbody>
</table>
APPENDIX 3

Questions for Narrative Interviews

Person with Semantic Dementia

The person is likely to have a language disorder so alternative rephrases have been suggested where necessary.

So tell me about you and your life.

Who are the important people in your life?
- Which people mean the most to you?
- Which people matter most to you?
- Use an analogy, e.g. which people would be in your premier league/top team?

What do you like doing with your time?
- What things, or activities, do you like to do?
- What do you like to do to keep active and busy?
- What do you like to do to relax and chill out?
- And what other things do you do?
- If you had a day free…what would you really like to do?

Where, which places, do you like to go?
- Do you go out and about locally…where?
- When you go out…where do you go?
- Do you go further afield…drive further/go on the train/plane?

What is important in your life now?
- What matters to you most now?
- What is the important…big league stuff …for you now?

What was the happiest time in your life?
- Thinking about your life, when were you happiest, contented…having a really nice time?

What are you most proud of?
- Thinking about your life, what has been really rewarding and pleasing for you?

What is not important in your life now?
- Are there things in life that don’t matter now, or are not as important as they used to be?
Family Carer

About the carer:

So tell me about you and your life.
Who are the important people in your life?
What do you like doing with your time?
Where, which places, do you like to go?
What is important in your life now?
When was the happiest time in your life?
What are you most proud of?
What is not important in your life now?
What helps you in your caring role?
What doesn’t help you in caring role?

Thinking about your spouse/friend relative:

So tell me a bit about them and their life.
Who are the important people in their life?
What do they like doing with their time?
Where, which places, do they like to go?
What is important in their life now?
When was the happiest time in their life?
What are they most proud of?
What is not important in their life now?

Joint Questions

Before I spoke to you both separately but today I wanted in this interview to think about the two of you together. So the following questions look at both of you:

So tell me about you two…you two together…whatever you like…anything about you two together?
What sort of things do you like to do together?
Do you have favourite places you like to go together?
What interests do you share?
What adjustments or changes have come in your relationship as a result of the semantic dementia?
What strategies do you use to keep/preserve your relationship?
What are the important things, or areas, in your lives now that you share?
When do you feel the strongest connection between each other?
What makes you laugh together?
## APPENDIX 4

### Neuropsychological Assessment Results

Table A4.1 – Neuropsychological test results

<table>
<thead>
<tr>
<th><strong>Peter - Case Study One</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACE-III</strong></td>
<td>27/100</td>
</tr>
<tr>
<td>Cambridge Naming Test</td>
<td>1/10</td>
</tr>
<tr>
<td>Cambridge Category Comprehension</td>
<td>28/64</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Sarah - Case Study Two</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACE-III</strong></td>
<td>36/100</td>
</tr>
<tr>
<td>Cambridge Naming Test</td>
<td>14/64</td>
</tr>
<tr>
<td>Cambridge Category Comprehension</td>
<td>24/64</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Ruby - Case Study Four</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACE-III</strong></td>
<td>52/100</td>
</tr>
<tr>
<td>Category Comprehension</td>
<td>28/32</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Ken - Case Study Five</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACE-III</strong></td>
<td>87/100</td>
</tr>
<tr>
<td>Category Comprehension Test</td>
<td>64/64</td>
</tr>
<tr>
<td>Cambridge Naming Test</td>
<td>62/64</td>
</tr>
<tr>
<td>Camel and Cactus</td>
<td>55/64</td>
</tr>
</tbody>
</table>
Dear Ms Kindell,

Study title: Sustaining everyday conversations for couples where one partner has semantic dementia: A case series intervention.

REC reference: 12/NW/0139

Thank you for your undated letter responding to the Committee's request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).
Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.crforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advertisement</td>
<td>Information for website (O) - 1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence of insurance or indemnity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP/Consultant Information Sheets</td>
<td>(N) 1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>Clinicians, service users, carers</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>CAPPCI adapted (P) - 1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>Ms J Kindell</td>
<td>02 February 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>Dr Karen Scargle</td>
<td>02 February 2012</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Key to documentation</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Personal Consultee letter (H)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Personal Consultee reply slip (I)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Role of the Personal Consultee in Research (U)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Information for Clinicians (K)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Contact form - Service users and carers (L)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Information for clinicians (at presentations) (M)</td>
<td>1</td>
<td>01 November 2011</td>
</tr>
<tr>
<td>Other: Consultee Information Sheet (D)</td>
<td>2</td>
<td>02 April 2012</td>
</tr>
<tr>
<td>Other: Consultee declaration form (G)</td>
<td>2</td>
<td>02 April 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Focus group - form R</td>
<td>1</td>
<td>22 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Carer (F)</td>
<td>2</td>
<td>02 April 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Focus group - form Q</td>
<td>1</td>
<td>22 March 2012</td>
</tr>
</tbody>
</table>
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12\NW\0139 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

Dr Ann Wakefield
Chair

Email: elaine.hutchings@northwest.nhs.uk

Enclosures: “After ethical review – guidance for researchers”

Copy to: Ms Lynne MacRae, R&D, University of Manchester

Ms Reagan Blythe, Pennine Care NHS Foundation Trust
29th June 2012

Ms Jacqueline Kindell
3rd Floor, Zachonis Building,
University of Manchester
Oxford Road,
Manchester
M13 9PL

Dear Ms Kindell,

Re: Research Governance Decision Letter

Project Reference: 1149
CSP Ref: 94606
Project Title: Sustaining everyday conversations for couples where one partner has semantic dementia: A case series intervention.
REG Ref Number: 12/NW/0139

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study. This also includes all amendments made up to the date of this letter. Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

Trust R&D approval covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached ‘Information for Researchers – Conditions of Research Governance Approval’ leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

You will need to contact us before any new researchers or staff join your team as they will need Trust permission before they start work on the project.

It is your responsibility to contact us a week prior to the expiry date we have recorded for this project to let us know if you wish to extend it, as we will need to send a new approval.
letter. You will also need to let us know immediately if for any reason the project finishes earlier.

It is a condition of our Trust approval that on completion of this study we are in receipt of an end of study report summary and a copy of the Ethics letter confirming that they have closed the study. We will remind you of this nearer the time. You will also be asked to complete an audit form for each year your study is supported by this Trust (including the year of its completion); this approval requirement and failure or refusal to complete it may result in Trust approval being withdrawn.

By beginning your research you are agreeing to all the terms and conditions as stated within this letter.

May I wish you every success with your research and if you have any queries do not hesitate to contact the R&D Team.

Yours sincerely,

Dr. Andy Mee
Research & Development Manager

cc: Research Governance Sponsor - University of Manchester
Employing Organisation - Pennine Care NHS Foundation Trust
Ms Allison Williams - Cavendish Ward, Laureate House.

Enc: Information for Researchers: Conditions of Research Governance Approval, Induction & ID Badge Information and TrustTECH Leaflet
Dear Jackie

Research and Development approval letter

Project Title: Sustaining everyday conversations for couples where one partner has semantic dementia: A case series intervention.


Thank you for submitting your research project for consideration by the Research and Development (R&D) Department. The project was reviewed by the R&D Panel in line with the ‘Research Governance Framework for Health and Social Care’ and in regards to its impact on resources for the Trust and its suitability within our research portfolio.

We have also verified the relevant documentation and approvals from all necessary regulatory agencies. These may include, but are not limited to, the National Research Ethics Service (NRES), the Medicines and Healthcare products Regulatory Agency (MHRA), and the Administration of Radioactive Substances Advisory Committee (ARSAC).

On this basis, we are now able to grant approval for your project at Pennine Care NHS Foundation Trust, subject to the terms and conditions listed below.

- The currently approved protocol is Version 2 dated 02nd April, 2012 and the approved documents, including the Participant Information Sheet and Informed Consent Form, are those listed in the Research Ethics Committee’s favourable opinion letter for this project dated 16th May, 2012. These must be the only versions in use.

- In the event of any amendment (substantial or minor) to the protocol or documentation, approval must be sought from the necessary regulatory agencies. Approval for the amendment must also be obtained from the Research and Development Department before implementation.

- Any significant deviation from the approved protocol or documentation must be notified to the R&D Department as soon as the issue is discovered.

- The Chief Investigator, local Principal Investigator and all other researchers working on the project must abide by and adhere to their specific responsibilities as detailed in the ‘Research Governance Framework for Health and Social Care’. They must also meet all UK statutory requirements, with particular significance, where applicable, to: the ‘Data Protection Act 1998’, ‘The Medicines for Human Use (Clinical Trials) Regulations 2004’, the ‘Mental Health Act 2007’, ‘The Human Tissue Act 2004’ and all subsequent amendments to these.

Project Approval Letter v1.1, 02/3/April 2012

Page 1 of 3
The only researchers approved to perform the research activities for this project at any Pennine Care site or involving any staff, service users or other persons under our duty of care are those listed on the SSI form and/or delegation log for Pennine Care.

continued on page 2...
23 July 2012

Ms Jacqueline Kindell
Clinical Research Fellow
University of Manchester
3rd Floor, School of Psychological Sciences
Oxford Road
Manchester M13 9PL

Dear Ms Kindell

Re: NHS Permission for Research

Project Reference: 744
Unique SPEAR Identifier: 1148
CSP Reference Number: 54008
IRAS/REC Reference Number: 12/NW/0130
Sponsor: University of Manchester
Protocol Version and Date: Version 2.0, 2 April 2012
Project Title: Sustaining everyday conversations for couples where one partner has semantic dementia: A case series intervention.
Date of Permission: 23 July 2012

Further to your request for permission to conduct the above research study at this Trust, we are pleased to inform you that this Trust has given NHS permission for the research. Your NHS permission to conduct research at this site is only valid upon receipt of a signed ‘Conditions for NHS Permission Reply Slip’ which is enclosed.

Please take the time to read the attached conditions for NHS permission. Please contact the R&D Office should you require any further information. You will need this letter as proof of NHS permission. Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

NHS permission for the above research has been granted on the basis described in the IRAS application form, Protocol and supporting documentation.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the Ethics Committee.

Greater Manchester West Mental Health NHS Foundation Trust
Research & Development Office
Room FO59, Hervey House
Bury New Road
 Prestwich
Manchester M23 9SR
Tel: 0161 772 3091/0894204262
Email: r&dlink@manchester.nhs.uk
jenifer.jennings@manchester.nhs.uk
wanda.talbot@wmmc.nhs.uk

Information for ID Badge if required:
Research Project Ref No: 744
Expiry Date: 31 October 2013
You must take this letter with you.

Chair: Alan Mardon
Chief Executive: Bev Humphrey

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Permission covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service-ward managers before commencing your research.

May I wish you every success with your research.

Yours sincerely

Dr Stephan Colgan
Medical Director and R&D Lead

cc: Sponsor, University of Manchester
    Local Collaborator, Professor John Keady
    CLRN, GM CLRN

Enc: Approval Conditions Leaflet
     Induction & ID Badge Information
Dear Ms Kindall

Study Title: Sustaining Everyday Conversations for Couples where one partner has Semantic Dementia: A Case Series Intervention.
REC Reference: 13/NN/0859
EudraCT Reference: N/A
CSP Reference: 94606
R&D Reference: 2012/2099/NEUR

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS Salford R&D and has gained NHS R&D approval from the following NHS Trusts:

- Salford Royal NHS Foundation Trust


It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The Research Passport Application Form, this can be obtained from web addresses: http://www.egresrnlh.nihsfage.nhs.uk/researchers/passports.html and http://www.hopec- academics.org.uk/ResearchPassports/Research%20Passports.htm. This form should be completed and returned, with a summary CV and recent (within 5 months) DBS to the address shown above.

It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study.

Research & Development
3rd Floor, Guy’s Building
St. Thomas’ Hospital
SE1

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Where clinical trials of investigational medicinal products are sponsored by Salford Royal NHS Foundation Trust or Salford Primary Care Trust, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate times) to R&D. For clinical trials of investigational medicinal products hosted within Salford Royal NHS Foundation Trust and Salford Primary Care Trust, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor’s Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study must gain full approval by the Ethics Committee and if appropriate, by the MHRA.

Please note, because the study has been adopted onto the NIHR Portfolio, and has been processed through QSP, all amendments must be submitted through the Lead CLRN. Please do not send any amendments to R&D directly, the Lead CLRN will inform us of any amendments to the study and will send any relevant information to us for our approval.

On completion of the study you are required to submit a ‘Declaration of End of Study’ form to the main R&D, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

[Signature]

Sue Gowland
R&D Manager
Approval for Case Study 3 – Data from Two Studies to be Linked

22nd January 2015 16:22

Dear Jacqueline,

Please accept my apologies for how long it has taken to respond to you.

The Chair has responded to advise he is happy to support the inclusion of patients data for the first and second study, particularly because the patient's family are fully informed and have no objections.

Best Wishes,

Nicola
Miss Nicola Burgess
CBS manager/REC Manager
0161 625 7830 nrescommittee.northwest-gmsouth@nhs.net

From: Jacqueline Kindell [jacqueline.kindell@manchester.ac.uk]
Sent: 25 November 2014 10:14
To: GMSouth NRESCommittee.NorthWest- (HEALTH RESEARCH AUTHORITY)
Subject: Ethics Question - Study REC ref 12/NW/0139

Dear Nicola

Lynne Macrae advised me to email you about an ethics issue I have with my study - ref above.

The study I am doing now, for my phd, had a pilot study, my master’s study. Both studies were approved by South Manchester REC. The study looks at everyday conversation issues in semantic dementia. A gentleman that took part in my masters has also taken part in my phd study. This means we have data three years apart and because this is dementia the data shows significant changes. These are clinically relevant and given this is a rare dementia, naturalistic data like this is not available in the literature currently.

The central issue is whether I would be able to tie these two data sets up and present this longitudinal view, and be covered from an ethical viewpoint OR if I should present him in my current research as a 'new' and separate participant, as technically these are two separate studies.

Some information relevant to this:

- For the current study his wife acted as a personal consultee, because he had lost capacity, he has since passed away.

- His wife is keen for us to show the changes, as she sees them as important, and is fine with us doing this, in fact she is a bit perplexed that I have said that I would need to check.
- When they both signed the masters study they both agreed: "I agree for the current researchers to carry out further analysis on the audio and videotape data after this project has finished."

- This analysis would be carried out by me and Professor Wilkinson, we did the analysis for the masters too. Professor John Keady has since joined the team and is now the main supervisor.

- The original masters data identifies a conversational behaviour, a positive strategy, that he is still doing, but because of deterioration in verbal output it would be hard to illustrate this within this phd data as effectively without the original masters data.

- Our original study, remains the only study in the literature examining everyday naturalistic conversation in this client group, there are no studies with longitudinal data and this is therefore a significant data set.

- Lynne advised that, if the REC are happy with this, University Governance can see no issues given the view of the family.

Would you be kind enough to let me know your views on this matter and how I might proceed. I'd be grateful for any advice you or the REC could provide me.

Thank you for taking time to consider these issues.

Jackie Kindell

Clinical Research Fellow
Tel 0161 306 7881
6th Floor - School of Nursing, Midwifery and Social Work
Jean McFarlane Building
University of Manchester
Oxford Road
Manchester M13 9PL
jacqueline.kindell@postgrad.manchester.ac.uk
APPENDIX 6

Ethical Challenges – Presented for Ethical Review

1. Videotaping in the home – invasion of privacy
Videotaping in the home is an intrusion into the privacy of the home situation and careful consideration of consent will be required for this. Following discussion the researcher will set up the video camera in an agreed location, usually in the lounge or dining area. She will show the caregiver and person with semantic dementia how to use it, but will not be present when videotaping takes place. The camera will be left in the home for 3 weeks and the caregiver and person with semantic dementia will be asked to record twenty minutes of conversation each week. In order to reduce the effects on privacy the couple will select where, when and for how long they want to video. Discussion will also take place regarding practical issues of interruptions to ensure videotaping always has the consent of all involved, e.g. other family members or other individuals who have given consent.

2. Videotaping in the home – instances of potential abuse.
There is a small risk that videotaping could detect inappropriate behaviours or instances of abuse. Participants will be under the care of a local speech and language therapist or a neurology or psychiatry team. This will enable referral on to relevant local services should concerns in this area arise in order to allow for assessment and management using local policies and procedures, e.g. Protection of Vulnerable Adults. Concerns of this nature have not arisen in other studies using this methodology in stroke and head injury. In addition, in order to reduce the likelihood of this occurring in this study, exclusion criteria will include any reported concerns from the responsible team/discipline regarding verbal or physical conflict in the household.

3. Discovery of unmet needs.
During the research process it may become clear that the person with semantic dementia and/or the family are in need of further assessment or service needs. The researcher is a specialist in dementia care working as part of a community mental health service for older people and is aware of the range of services available. In these instances the researcher will discuss this with the person with semantic dementia and/or their family, and if they wish for further assessment or services, the researcher will contact in writing the local speech and language therapist and/or neurology/psychiatry team to outline this need. Where appropriate a referral to social care services or other relevant agencies (e.g. Alzheimer’s Society) will be made.

4. Participant distress - videotaping
The person with semantic dementia or the caregiver may become distressed by the video process. Because of the design of the study the person with semantic dementia will always be with their caregiver during videotaping. This allows for the caregiver, and the person where possible, to have control of this process. Caregivers will be asked to monitor for any signs of distress in their partner or themselves, arising out of the video process, and to stop if this occurs. Following consent the researcher will demonstrate how the camera works including carrying out a ‘dry run’ by videotaping
the couple. She will then show them the tape on the camera screen. This, and
discussion with both parties, will give an opportunity to ascertain if any party
becomes distressed or uncomfortable with videotaping or viewing themselves on
screen. If such distress is consistent and individuals cannot be reassured, either at
this point or later during therapy sessions, then involvement in the study will be
terminated.

5. Participant distress - neuropsychology
Neuropsychological assessment will require the careful delivery of assessments at a
pace the person with semantic dementia can manage and with thorough explanation
of their function. Sensitivity to restlessness or signs of distress will be monitored.
Should this occur the process will be stopped. The researcher has extensive
experience in this area and assessments are likely to include both easier and more
difficult tests and order and delivery of tests will take this into account, as well as
standardised performance cut offs where consistent failure on tasks is present.

6. Participant distress - interviews
Interviews for both parties could be distressing. Reflecting on skills lost and changes
in relationships can be upsetting. The researcher will ensure topics are discussed
sensitively and any distress dealt with appropriately at the time. The researcher has
training in counselling skills and would be able to recognise those situations that
might require further specialist counselling or psychological therapy. The local
speech and language therapist or responsible team will act as a point of contact for
this information locally in order to facilitate onward specialist referral.

7. Participant distress - general issues
The researcher will be available for telephone and face to face discussion if concerns
arise. It will be stressed that participants are free to drop out of the research at any
time. All aspects of the research will be carried out sensitively by the researcher,
who is experienced in the care of people with dementia and their caregivers and who
understands the complex needs of this group.

8. Consent issues
Due to their semantic dementia some people may find it difficult to understand the
study, or be able to express their views unequivocally, in order to give fully informed
consent. Jacqueline Kindell is a specialist speech and language therapist in dementia
care and has experience with respect to issues of clinical consent and facilitating this
in those with a language disorder. She has had further training with respect to taking
consent for research purposes (University of Manchester module ‘Managing
Research in Clinical Settings, Masters in Clinical Research). Simplified written and
verbal information will be provided to ensure information is accessible and therefore
to facilitate informed consent. Information provision will be facilitated where
possible using verbal explanation, simplified written material (with pictorial
additions and in a ‘talking mats’ (Talking Mats 2011) format where necessary)
alongside demonstration of each research step. All caregivers involved in the
research from their own perspective must be over 18.

People with semantic dementia who are assessed as lacking capacity to consent for
themselves are also included in order to allow for the study to reflect the range and
progression of this significant language disorder. In these instances there must be a
caregiver willing to act as a personal consultee to give advice regarding the person’s previous views and current situation. It is likely that this will be the main caregiver, who, because of the design of the study, will be participating alongside the person. If the caregiver identifies another family member to act as consultee this individual will be contacted. The decision to include people who are unable to consent will, therefore, be made with close collaboration between the researcher and the personal consultee, considering the potential participants past wishes and views and current situation. The advice provided by the British Psychological Society (2008) ‘Conducting Research with People not having the Capacity to Consent to their Participation’ will be used to guide and checklist this process.
APPENDIX 7
Examples of Information Sheets

1. Participant information sheet A.
2. Participant information sheet B (pictorial).
3. Carer information sheet.
4. Personal consultee information sheet.
Research Study: Sustaining everyday conversations for couples where one partner has semantic dementia

Participant Information Sheet (A)

Principle Investigator: Jackie Kindell (Speech and Language Therapist)

CONTACT:

Tel: 0161 716 4505 or 0161 306 7881

email: jacqueline.kindell@postgrad.manchester.ac.uk

Supervisor:

Professor John Keady
Floor 6
School of Nursing, Midwifery and Social Work
The University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL
Telephone: 0161 306 7854

Version 3 – 11/07/13
We would like to invite you to take part in our research study. Before you decide if you want to be involved we would like to explain:

- Why the research is being done
- What would be involved.

Our researcher will go through this form with you and answer any questions you may have. This sheet is for you to keep. We will give you time to think about the study and talk to your family. Take time to decide if you would like to take part.

**What is the purpose of this study?**

This study aims to test out a communication support and therapy package for people with a communication difficulty called semantic dementia. So far most studies into this condition have looked at how people score on language 'tests'. There have been no studies as yet looking at how talking is affected in everyday situations and what would help people with this condition and their families cope with these difficulties on a day to day basis.

In this study we want to know more about everyday communication difficulties and how we should better support people. We want to see if we can work in partnership with families to design and test out individually tailored advice around communication and more general support needs. The reason we want to do this is because we think this may help services, both in this country and internationally, to give better advice to people with this condition in the future.

**Why have I been invited to take part?**

Your doctor has given you a diagnosis of semantic dementia. This is the condition we are studying. You have been in contact with a local NHS clinician and they thought that you might be interested in taking part.

**Do I have to take part in the study?**

No…you do not have to take part in the research study if you do not want to. Taking part is voluntary, so it is up to you whether to take part or not. If you do decide to take part we will ask you to sign a consent form. You can change your mind at any time and withdraw from the study. You do not have to give a reason for this and this would not affect the care and treatment you get now or in the future.

**What will happen to me if I take part?**

Our researcher Jacqueline Kindell will visit you and your family at home to carry out the research. She will explain all the steps involved. The study will begin with assessment and information gathering, followed by advice and therapy and then reassessment. We aim to carry this out twice, so at the beginning of the study and then again twelve months later.

**What is involved in the first phase of the study?**

**ASSESSMENT** - The study begins with assessment and there are three main parts to this, all carried out over five visits to your home. Visits will take 2-3 hours and some tasks will involve you, some with your family and some with you both. We will pace these tasks so that participants are given a rest between tasks.
Tests of memory and language – This should take about 2 ½ hours in all but this is done in smaller chunks over the visits. This will tell us about how your condition affects these areas.

Videotaping conversations – We would like to video you talking to at least one other member of your family. This should take about twenty minutes a week over three weeks and we will leave a video camera with you to do this. This will let us look at natural conversations and how these are affected. Together we can look at the video clips in therapy so we can see real life examples of difficulties and explore ways to manage them.

Getting to know the person and the family – A vital step is getting to know you, and how changes in communication have affected you and your family. This involves interviewing you and a family member about communication issues in everyday life and how you manage them. We would also like to ask you about your life story, interests and the things that are important to you both. This helps us know for example what you like to talk about. Where necessary to support communication needs we can look at photographs, memorabilia or objects that are important to you to help this process. We will audiotape these interviews.

Research Measures – To help us examine the effects of therapy we would also like you to complete some short questionnaires around quality of life.

THERAPY - After assessment we aim to carry out some advice and information sessions with you and your family. This will take 6-8 sessions each lasting about an hour, usually weekly. We will explore the results of the assessment with you, look at the video clips together and work out realistic ways to help, and cope with, communication difficulties in everyday life. These sessions will be tailored to your individual situation and the advice we work out can be logged into a ‘Communication Passport’. This is an on-going record of strategies, conversation topics etc. that support conversation.

If you feel it would help, we can visit any clubs or social groups you attend to explain your condition and the best ways to help with your communication. We would only do this if you and your relative/spouse thought this would help. We could also see if communication is any different in such settings and this may help inform our intervention. We could also take photographs during such visits that could go in your communication passport, to help support talking around such topics.

REASSESSMENT - We need to know how you have found the therapy process and if it has helped in any way and so we would like to interview you and your family at the end of the therapy. This will involve two more visits to your house. We would also like you to video tape some more conversations at home at this point. This would again involve you keeping a video camera and recording twenty minutes of everyday talking a week for three weeks. All visits will be arranged at your convenience. We can arrange visits around activities, appointments and holidays so that the research does not interrupt your schedule too much.
How will the videotaping work?
Jacqueline Kindell, our researcher, will bring the video-camera to your house. She will show you how it works. Together you can decide where to set it up and Jacqueline will set it ready to use. Jacqueline will then leave it with you for three weeks. You will be asked to record up to twenty minutes of everyday conversation per week talking to one or more members of your family. It is sometimes best to do this in a number of smaller chunks. You can talk about anything you like while being videotaped. This is up to you. This can be done during everyday activities such as while having a meal, coffee or washing up. We just want to record everyday conversations.

What is involved in the second phase of the study?
All the activities described above are carried out over the first 6 months of the study period. Over the next 5 months we will keep in touch with you over the phone and you can ring us at any time. We will also visit in the middle of this just to keep in touch and see how you are getting on. At 12 months we will carry out another block of assessment and therapy, but because of the work we have already done together there will be less time needed for some of the tasks. The tasks required will be the same as within the first block but with 4 assessment visits, 4 therapy visits and 2 reassessment visits to your home, so 10 visits in all.

What would happen if I was ill during the study period?
We can rearrange, or delay, appointments if you or your relative/spouse is unwell for short periods during the study. If however, illness or change of circumstance, is over a longer duration we can discuss this with you and your family. In these instances we understand that it may be necessary to halt involvement in the study. We would like, with your agreement, to keep and use any data gathered up to this point, as all data can help us understand everyday communication difficulties in semantic dementia.

Will my part in the study be kept confidential?
Yes. We follow ethical and legal practice and all information about you will be handled in confidence. This means only the research team will have access to the information you give us. On all written documents we change your name and any other personal details and when we publish the findings we change any names or other details so that you cannot be identified in any way. Any quotes we use in publications will therefore be anonymised. We will store any information you give us on a secure computer system at the university that is protected by a password. This means only those people who have the password can see the information. All written documents are stored in a locked cabinet in a locked office.

Who will see the videotapes?
The research team will view the videotapes and you will see them in our therapy sessions. The videotapes will be stored on a password protected university computer system. With your additional consent we would like to use video recordings for educational purposes, e.g. to teach health professionals and students and for further research purposes. You do not have to agree to these additional requests. If either of you do not agree to the use of the video for teaching or further research, it will not stop you from taking part in the current study.
Transcription Services
Due to the volume of information to type out we may at times use a transcription service to type out interviews and video conversations. We would only use University approved professional transcription services for this purpose. They are bound by contractual arrangements with the University to maintain security and confidentiality of information. We can place data within a secure area on our computer system and give the service a code and password to access only what they need and this therefore maintains security.

Who will know I am taking part in this study?
We would like with your consent to inform your GP you are involved in this study. If you are involved with a local speech and language therapist, neurologist or mental health service we would like to inform them too as this may be of relevant to them. We will inform them about the final results because this might help them understand your condition better. If during the research you, your family or the researcher feel that you need more advice about managing your condition or situation we can discuss this with you and refer on to other services if necessary. All information will remain confidential within these stated limits, unless disclosure is essential to protect you or others from the risk of significant harm, or disclosure is required by law. Examples of this would be if you, or a family member, were shown to be at risk of physical violence or there was a disclosure of vulnerability or abuse. In such cases we would need to access the appropriate services in order to provide the necessary support and help required.

What are the risks or disadvantages of taking part?
The main disadvantage of taking part in this research is the inconvenience and intrusion into your home. We will try to keep this to a minimum at all times and make appointment times to suit you. If any aspect of the research is upsetting to you we can stop. We can arrange for support from your speech therapist, or local neurology or mental health service, if you need someone to talk to outside of the research project. In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or participating NHS Trusts but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

What are the benefits of taking part?
We very much hope that taking part in this study will help you and your family understand your condition better and give you tips on how to manage your communication as best you can. It may also help others such as your GP understanding how your condition affects you. In broader terms we hope to find out more about semantic dementia so that health services in this country and internationally, can provide better advice to people with this condition.

What happens if the video camera is lost or broken?
The video camera belongs to the University of Manchester. We understand that you/your relative will take care of it but also that accidents can happen. If the camera is broken or lost, do not worry, you/your relative would not be expected to pay for any damage or for it to be replaced. If it is lost any recordings on the camera would also be lost with it and the University would be unable to retrieve these.
What will happen to the results of the research?
Before we write up the final results we will visit you and your family at home to discuss them. We can talk about what the results mean and add any missing information. The results will form part of a Doctoral Thesis at the University of Manchester. The results will be written up for professional journals and other relevant information resources. We will make sure a copy of this is available for you if you wish. We will also present the findings at professional conferences. You will not be identifiable in any of these documents as we change names, places and any other identifiable information. We hope this will help others understand semantic dementia better.

What will happen to the videos at the end of the study?
Semantic dementia is a relatively rare condition. We would like the opportunity to retain the video tapes after the end of the study for:

- Further research
- Conference presentations
- Research presentations
- Teaching

In order to be sure that we know how you both would like us to use these recordings we would like to check with you whether we may show them:

- To use in further studies at the University of Manchester examining conversation in semantic dementia.
- To use selected video clips at conferences to illustrate the results of this study.
- To show other researchers interested in semantic dementia and conversation to demonstrate our findings.
- To teach speech and language therapists and other health and social care professionals and students in training for these professions about semantic dementia.

We would not use the videos outside of these purposes. All videos will be kept securely. There are specific sections on the consent form in order for you to agree or disagree to these uses. If you do NOT agree to these uses, this will not affect your ability to participate in the research project.

Who has reviewed this study?
This study has been reviewed by experts at the University of Manchester. It has been reviewed and given a favourable opinion by the North West 6 Greater Manchester South Research Ethics Committee.

Who should I contact if I have a question or problem during the study?
Please feel free to ask questions of any member of the research team at any time (see numbers on front sheet). If you have any unresolved concerns or complaints you can contact one of the University Research Practice and Governance Coordinators on 0161 275 7583 (email research-governance@manchester.ac.uk).

Thank you for taking the time to consider this study.
Research Study:

Sustaining everyday conversations for couples where one partner has semantic dementia

Participant Information sheet: Shortened format (B)

Principle Investigator:

Jackie Kindell

CONTACT:

Telephone: 0161 716 4505 or 0161 306 7881

email: jacqueline.kindell@postgrad.manchester.ac.uk

Supervisor:

Professor John Keady
Floor 6
School of Nursing, Midwifery and Social Work
The University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL
Telephone: 0161 306 7854

Form B - Version 3 – 11/07/13
**Invitation:**

You are invited to take part in some **research** for people with communication difficulties. The condition you have can affect your talking.

We are studying this condition, and how to help.

**Please read** this information carefully.

And **ask** any questions.

Take time to think about taking part.
Why me?

You are invited to take part because:

- We are studying conditions that affect the brain’s abilities with talking and understanding.

- This often makes finding the words difficult.
We have been told you sometimes have these difficulties.

This research study is about how **conversations** are affected when talking to your relatives and friends.

Sometimes talking is easy:

But sometimes it is not:
This can be frustrating for everyone:

We would like to know the best ways to help to make these things easier:
We would like to do the following:

1) Video conversations with your family, or friend and you.

We can leave a video camera for you to do this:

2) Language and memory tests.
3) Find out more about you by doing interviews with you and your family:

It might help if you show us photographs important to you:
Then we would like to find the best ways to help.

We will visit you and your family at home for a period of therapy. We will:

Look at the videos together:

And work out the best ways to help talking.

We could, if you like, visit any social clubs you go to:

We could help explain any communication needs you have.
We could take photos to help with talking about these things:

The research will be done at your home.

You can stop for a break any time you feel tired.
With your permission we will tell your GP and your NHS speech and language therapist or other clinician you are taking part.

**Taking Part – it’s up to you…**

You do not have to take part. It’s your choice.

If you do, you will need to sign a consent form.

You can stop at any time.

It’s your choice.

It’s OK to stop.

You don’t have to tell us why.

If you have to leave the study early because you are ill or there is a change in your circumstances, we would like to keep any data we have gathered up till that point.

No data is wasted, it can all help us understand this condition better.
Privacy and Confidentiality

All the information we collect is confidential.

Videos and written details will be kept on a university computer that is protected with a password.

Copies of videos and written details will be locked in a cabinet.
This is the research team:

Jackie

Ray

The researchers will look at your videos and interviews.

Jackie and Ray are speech and language therapists and John is a nurse.

We all have experience of working with people with various communication difficulties.
We will ask your permission to show the videos to people wanting to learn about your condition, eg:

- Other researchers
- Health care professionals
- Students

But you do not have to agree to this.

After the study we may publish the results in journals

and present them at conferences.
We may include quotes from your conversations and information about your condition.

We will change everything that could identify you (eg your name and where you live). No one will know it is you and your family:

You can have a copy of the results.

The research is paid for by the Dunhill Medical Trust.

The Universities of Manchester and Sheffield are supervising it.
If there is a **problem** or you are **worried**, speak to the **researchers**. They will try to fix it.

If you need to **complain**, contact a **University Research Practice and Governance Co-ordinator**:
Tel: 0161 2757583 / 2758093
Email: research-governance@manchester.ac.uk

If you have any **questions** telephone:

Jackie Kindell
0161 716 4505 or 306 7881

Thank you.
Research Study: Sustaining everyday conversations for couples where one partner has semantic dementia.

Participant Spouse/Relative Information - Sheet (C)

Principle Investigator: Jackie Kindell (Speech and Language Therapist)
Telephone: 0161 716 4505 or 0161 306 7881

Supervisor:

Professor John Keady
Floor 6
School of Nursing, Midwifery and Social Work
The University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

Telephone: 0161 306 7854

Version 3 – 11/07/13 (sheet C)
We would like to invite you to take part in our research study. Before you decide if you want to be involved we would like to explain:

- Why the research is being done.
- What would be involved.

Our researcher will go through this form with you and answer any questions you may have. This sheet is for you to keep. We will give you time to think about the study and talk to your family. Take time to decide if you would like to take part.

**What is the purpose of this study?**
This study aims to test out a communication support and therapy package for people with semantic dementia and their family. So far most studies in this area have looked at how people score on language ‘tests’. There have been no studies as yet looking at how talking is affected in everyday situations and what would help people cope with these difficulties on a day to day basis.

In this study we want to know more about everyday communication difficulties and how we should better support people. We want to see if we can work in partnership with families to design and test out individually tailored advice around communication and more general support needs. The reason we want to do this is because we think this may help services, both in this country and internationally, to give better advice to people with this condition in the future.

**Why have I been invited to take part?**
Your relative/spouse has a diagnosis of a progressive communication difficulty called semantic dementia. This is the condition we are studying. Your relative/spouse has been in contact with a local NHS clinician and they thought that you might both be interested in taking part in this study.

**Do I have to take part in the study?**
No. You do not have to take part in the research study if you do not want to. Taking part is voluntary, so it is up to you whether to take part or not. If you do decide to take part we will ask you to sign a consent form. You can change your mind at any time and withdraw from the study. You do not have to give a reason for this and this would not affect the care and treatment your relative/spouse gets now or in the future.

**What will happen to me if I take part?**
Our researcher Jacqueline Kindell will visit you both at home to carry out the research. She will explain all the steps involved. The study will begin with assessment and information gathering, followed by advice and therapy and then reassessment. We aim to carry this out twice, so at the beginning of the study and then again one year later.
What is involved in the first phase of the study?

**ASSESSMENT** – The study begins with assessment and there are three main parts to this, all carried out over five visits. Visits will usually take 2 – 2 ½ hours and some tasks will involve you, some with your relative/spouse and some with you both. We will pace these tasks so that you are given a rest between tasks.

Tests of memory and language – These are tests with your relative/spouse and should take about 2 ½ hours in all, but this is done in smaller chunks over the visits. This will tell us about how their condition affects these areas.

Videotaping conversations – We would like to video you and your relative/spouse talking together so we can look in more detail at communication difficulties. This should take about twenty minutes a week over three weeks and we will leave a video camera in the home to do this. This will let us look at natural conversations and how these are affected. We can then look at the video clips in therapy so we can see real life examples of difficulties and explore ways to manage them.

Getting to know your relative/spouse and you - A vital step is getting to know how changes in communication have affected you both. This involves interviewing you and your relative/spouse about communication issues in everyday life and how you manage them. We would also like to interview you to find out about their story, interests and the things that are important to you both. This helps us know for example what you like to talk about. Where necessary, to support the communication needs of your relative/spouse, we can look at photographs, memorabilia or objects that are important to them to help them express themselves. We will audiotape these interviews.

Research Measures – To help us examine the effects of therapy we would also like you and your relative/spouse to complete some short questionnaires around quality of life and coping.

**THERAPY** - After assessment we aim to carry out some advice and information sessions with you both and any other members of your family who wish to attend. This will take 6-8 sessions each lasting about an hour, usually weekly. We will explore the results of the assessment with you, look at the video clips together and work out realistic ways to help, and cope with, communication difficulties in everyday life. These sessions will be tailored to your individual situation and the advice we work out can be logged in a ‘Communication Passport’. This is an ongoing record of strategies, conversation topics etc. that support conversation.

If you feel it would help, we can visit any clubs or social groups that your relative/spouse attends to explain their condition and the best ways to help with communication. We would only do this if you and your relative/spouse thought this would help. We could also see if communication is any different in such settings and this may help inform our intervention. We could also take photographs during such visits that could go in your relative/spouses communication passport, to help support talking around such topics.
**REASSESSMENT** - We need to know how you both have found the therapy process and if it has helped in any way and so we would like to interview you both, if possible, at the end of the therapy. This will involve two more visits to your house. We would also like you both to video some more conversations at home at this point. This would again involve you keeping a video camera and recording twenty minutes of everyday talking a week for three weeks. All visits will be arranged at your convenience. We can arrange visits around activities, appointments and holidays so that the research does not interrupt your schedule too much.

**How will the videotaping work?**
Jacqueline Kindell, our researcher, will bring the video-camera to your house. She will show you how it works. Together you can decide where to set it up and Jacqueline will set it ready to use. Jacqueline will then leave it with you for three weeks. You will be asked to record up to twenty minutes per week of normal everyday conversation talking together with your relative/spouse. It is sometimes best to do this in a number of smaller chunks. You can talk about anything you like while being videotaped. This is up to you. This can be done during everyday activities such as while having a meal, coffee or washing up. We just want to record everyday conversations.

**What is involved in the second phase of the study?**
All the activities described above are carried out over the first 6 months of the study period. Over the next 5 months we will keep in touch with you over the phone and you can ring us at any time. We will visit half way through just to keep in touch. At 12 months we will carry out another block of assessment and therapy, but because of the work we have already done together there will be less time needed for some of the tasks. The tasks required will be the same as within the first block but with 4 assessment visits, 4 therapy visits and 2 reassessment visits to your home, so 10 visits in all.

**What would happen if anyone was ill during the study period?**
We can rearrange, or delay, appointments if you or your relative/spouse is unwell for short periods during the study. If however, illness or change of circumstance is over a longer duration we can discuss this with you. In these instances we understand that it may be necessary to halt involvement in the study. We would like, with your agreement, to keep and use any data gathered up to this point, as all data can help us understand everyday communication difficulties in semantic dementia.

**Will my part in the study be kept confidential?**
Yes. We follow ethical and legal practice and all information about you will be handled in confidence. This means only the research team will have access to the information you give us. On all written documents we change your name and any other personal details and when we publish the findings we change any names or other details so that you cannot be identified in any way. Any quotes we use in publications will therefore be anonymised. We will store any information you give us on a secure university computer that is protected by a password and ‘encrypted’. This means only those people who have the password can see the information. All written documents are stored in a locked cabinet in a locked office.
Who will see the videotapes?
The research team will view the videotapes and you will see them in our therapy sessions. The videotapes will be stored on a password protected computer. With your additional consent we would like to use video recordings for educational purposes, e.g. to teach health professionals and students and for further research purposes. You do not have to agree to these additional requests. If either of you do not agree to the use of the video for teaching or further research, it will not stop you from taking part in the current study.

Transcription Services
Due to the volume of information to type out we may at times use a transcription service to type out interviews and video conversations. We would only use University approved professional transcription services for this purpose. They are bound by contractual arrangements with the University to maintain security and confidentiality of information. We can place data within a secure area on our computer system and give the service a code and password to access only what they need and this therefore maintains security.

Who will know we are taking part in this study?
We would like, with consent from you both, to inform your relative/spouse’s GP that you are both involved in this study, and also their speech and language therapist or Neurologist/mental health service if relevant. We will inform them about the final results because this might help them understand the condition better. If during the research you, or the researcher, feel that you need more advice about managing the condition or situation we can discuss this with you and refer on to other services if necessary. All information will therefore remain confidential within these stated limits, unless disclosure is essential to protect you or others from the risk of significant harm, or disclosure is required by law. Examples of this would be if you, or a family member, were shown to be at risk of physical violence or there was a disclosure of vulnerability or abuse. In such cases we would need to access the appropriate services in order to provide the necessary support and help required.

What are the risks or disadvantages of taking part?
The main disadvantage of taking part in this research is the inconvenience and intrusion into your home. We will try to keep this to a minimum at all times and make appointment times to suit you. If any aspect of the research is upsetting to you we can stop. We can arrange for support from your speech therapist, or local neurology or mental health service, if you or your relative/spouse needs someone to talk to outside of the research project about the condition. In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or participating NHS Trusts but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

What are the benefits of taking part?
We very much hope that taking part in this study will help you both understand this condition better and give you tips on how to manage communication as best you can. It may also help others, such as your GP, understand the condition. In broader terms we hope to find out more about semantic dementia so the health service can provide better advice to people with this condition.
What happens if the video camera is lost or broken?
The video camera belongs to the University of Manchester. We understand that you/your relative will take care of it but also that accidents can happen. If the camera is broken or lost, do not worry, you/your relative would not be expected to pay for any damage, or for it to be replaced. If it is lost any recordings on the camera would also be lost with it and the University would be unable to retrieve these.

What will happen to the results of the research?
Before we write up the final results we will visit you both at home to discuss them. We can talk about what the results mean and add any missing information. The results will form part of a Doctoral Thesis at the University of Manchester. The results will be written up for professional journals and other relevant information resources. We will make sure a copy of this is available for you if you wish. We will also present the findings at professional conferences. You will not be identifiable in any of these documents as we change names, places and any other identifiable information. We hope this will help others understand semantic dementia better.

What will happen to the video and audiotapes at the end of the study?
Semantic dementia is a relatively rare condition. We would like the opportunity to retain the video clips after the end of the study for:

- Further research
- Conference presentations
- Research presentations
- Teaching

In order to be sure that we know how you both would like us to use these recordings we would like to check with you whether we may show them:

- To use in further studies at the University of Manchester examining conversation in semantic dementia.
- To use selected video clips at conferences to illustrate the results of this study.
- To show other researchers interested in semantic dementia and conversation to demonstrate our findings.
- To teach speech and language therapists and other health and social care professionals and students in training for these professions about semantic dementia.

We would not use the videos outside of these purposes. All videos will be kept securely. There are specific sections on the consent form in order for you to agree or disagree to these uses. If you do NOT agree to these uses, this will not affect your ability to participate in the research project.

Who has reviewed this study?
This study has been reviewed by experts at the University of Manchester. It has been reviewed and given a favourable opinion by the North West 6 Greater Manchester South Research Ethics Committee.
Who should I contact if I have a question or problem during the study?
Please feel free to ask questions of any member of the research team at any time (see numbers on front sheet). If you have any unresolved concerns or complaints you can contact one of the University Research Practice and Governance Coordinators on 0161 275 7583 (email research-governance@manchester.ac.uk).
Thank you for taking the time to consider this study.
Research Study: Sustaining everyday conversations for couples where one partner has semantic dementia

Sheet D - Consultee Information Sheet

Principle Investigator: Jackie Kindell (Speech and Language Therapist)
Telephone: 0161 716 4505 or 0161 306 7881

email: jacqueline.kindell@postgrad.manchester.ac.uk

Supervisor:

Professor John Keady
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University of Manchester

Telephone: 0161 306 7854

Form D - Version 3 – 11/07/13
Introduction

We feel your relative/spouse/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we would like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence. If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration form. We will then give you a copy to keep.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/spouse/friend should be withdrawn. If you decide that they would not wish to take part it will not affect the standard of care they receive in any way. If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/spouse/friend.
We would like to invite your relative/spouse/friend to take part in our research study. Before you decide if you think they would want to be involved we would like to explain:

- Why the research is being done.
- What would be involved.

Our researcher will go through this sheet with you and answer any questions you may have. This sheet is for you to keep. We will give you time to think about the study and talk to your relative/spouse/friend and your family. Take time to decide if you think they would like to take part.

**What is the purpose of this study?**
This study aims to test out a communication support and therapy package for people with semantic dementia and their family. So far most studies in this area have looked at how people score on language ‘tests’. There have been no studies as yet looking at how talking is affected in everyday situations and what would help people with this condition and their families cope with these difficulties on a day to day basis.

In this study we want to know more about everyday communication difficulties and how we should better support people. We want to see if we can work in partnership with the person and their families to design and test out individually tailored advice around communication and more general support needs. The reason we want to do this is because we think this may help services, both in this country and internationally, to give better advice to people with this condition in the future.

**Why has my relative/spouse/friend been invited to take part?**
Your relative/spouse has a diagnosis of a progressive communication disorder called semantic dementia. This is the condition we are studying. Your relative/spouse/friend has been in contact with a local NHS clinician and they thought that they might be interested in taking part in this study.

**Does my relative/spouse/friend have to take part in the study?**
No. They do not have to take part in the research study if they do not want to or if you feel it would not be appropriate. Taking part is voluntary, so it is up to you and your relative/spouse/friend whether s/he takes part or not. If you do think s/he would not object to taking part, we will ask you to sign a consultee declaration form. You can change your mind at any time and withdraw the person from the study. You do not have to give a reason for this and this would not affect the care and treatment your relative/spouse/friend gets now or in the future.

**What will happen if my relative/spouse/friend takes part?**
Our researcher Jacqueline Kindell will visit your relative/spouse/friend and their main family carer at home to carry out the research. She will explain all the steps involved. The study will begin with assessment and information gathering, followed by advice and therapy and then reassessment. We aim to carry this out twice, so at the beginning of the study and then again twelve months later.
What is involved in the first phase of the study?

**ASSESSMENT** – The study begins with assessment and there are three main parts to this, all carried out over five visits. Visits will usually take 2 – 2 ½ hours and some tasks will involve the carer, some with your relative/spouse/friend and some with both. We will pace these tasks so those involved are given a rest between tasks.

**Tests of memory and language** – These are tests with your relative/spouse/friend and should take about 2 ½ hours in all but this is done in smaller chunks over the visits. This will tell us about how their condition affects these areas.

**Videotaping conversations** – We would like to video the family and your relative/spouse/friend talking together so we can look in more detail at communication difficulties. This should take about twenty minutes a week over three weeks and we will leave a video camera in the home to do this. This will let us look at natural conversations and how these are affected. We can then look at the video clips in therapy so we can see real life examples of difficulties and explore ways to manage them.

**Getting to know the person and the family** – A vital to step is getting to know how changes in communication have affected everyone involved. This involves interviewing the family carer and your relative/spouse/friend about communication issues in everyday life and how they manage them. We would also like to carry out interviews with the family and your relative/spouse/friend to find out about their story, interests and the things that are important to them. This helps us know, for example, what they like to talk about. Where necessary to support communication needs we can look at photographs, memorabilia or objects that are important to your relative/spouse/friend to help them express themselves. We will audiotape these interviews.

**Research Measures** – To help us examine the effects of therapy we would also like the person and the carer to complete some short questionnaires around quality of life and coping.

**THERAPY** - After assessment we aim to carry out some advice and information sessions with your relative/spouse/friend and the carer, and any other members of the family who wish to attend. This will take 6-8 sessions each lasting about an hour, usually weekly. We will explore the results of the assessment, look at the video clips together and work out realistic ways to help, and cope with, communication difficulties in everyday life. These sessions will be tailored to the individual situation and the advice we work out can be logged in a ‘Communication Passport’. This will be an on-going record of strategies, conversation topics etc. that support conversation.

If you feel it would help, we can visit any clubs or social groups that your relative/spouse attends to explain their condition and the best ways to help with communication. We would only do this if you and your relative/spouse thought this would help. We could also see if communication is any different in such settings and this may help inform our intervention. We could also take photographs during such
visits that could go in your relative/spouse’s communication passport, to help support talking around such topics.

**REASSESSMENT** - We need to know how those involved found the therapy process and if it has helped in any way. Therefore we would like to interview both parties, if possible, at the end of the therapy. This will be done over two home visits. We would also like to video some more conversations at home at this point. This would again involve keeping a video camera at home and the family carer and your relative/spouse/friend recording twenty minutes of everyday talking a week for three weeks. All visits will be arranged at your relative/spouse’s convenience. We can arrange visits around activities, appointments and holidays so that the research does not interrupt their schedule too much.

**How will the videotaping work?**
Jacqueline Kindell, our researcher, will bring the video-camera to the home. She will demonstrate how it works. Together the family and your relative/spouse/friend can decide where to set it up, and Jacqueline will set it ready to use. Jacqueline will then leave it in the home for three weeks. The request will be to record up to twenty minutes per week of normal everyday conversation. This can be done during everyday activities such as while having a meal, coffee or washing up. It is sometimes best to do this in a number of smaller chunks. They can talk about anything they like while being videotaped. This is up to them. We just want to record everyday conversations.

**What is involved in the second phase of the study?**
All the activities described above are carried out over the first 6 months of the study period. Over the next 5 months we will keep in touch with the main carer over the phone and they can ring us at any time. We will visit half way along to keep in touch. Then at the end of the year we will carry out another block of assessment and therapy, but because of the work we have already done together there will be less time needed for some of the tasks. The tasks required will be the same as within the first block but with 4 assessment visits, 4 therapy visits and two reassessment visits to the home, so 10 visits in all.

**Will my relative/spouse/friend’s part in the study be kept confidential?**
Yes. We follow ethical and legal practice and all information about them will be handled in confidence. This means only the research team will have access to the information given to us. On all written documents we change names and any other personal details and when we publish the findings we change any names or other details so that no one can be identified in any way. Any quotes we use in publications will therefore be anonymised. We will store any information on a secure computer that is protected by a password and ‘encrypted’. This means only those people who have the password can see the information. All written documents are stored in a locked cabinet in a locked office.

**Who will see the videotapes?**
The research team will view the videotapes and the family carer and your relative/spouse/friend will see them in our therapy sessions. The videotapes will be stored on a password protected computer. With your additional agreement we would like to use video recordings for educational purposes, e.g. to teach health
professionals and students and for further research purposes. You do not have to agree to these additional requests. If you do not agree to the use of the video for teaching or further research, it will not stop your relative/spouse/friend from taking part in the current study.

**Transcription Services**

Due to the volume of information to type out we may at times use a transcription service to type out interviews and video conversations. We would only use University approved professional transcription services for this purpose. They are bound by contractual arrangements with the University to maintain security and confidentiality of information. We can place data within a secure area on our computer system and give the service a code and password to access only what they need and this therefore maintains security.

**Who will know my relative/spouse/friend is taking part in this study?**

We would like, with your agreement, to inform your relative/spouse’s GP that they are involved in this study, and also his/her/ speech and language therapist or Neurologist/mental health service if relevant. We will inform them about the final results because this might help them understand the condition better. If during the research you, the family or the researcher feel that you need more advice about managing this condition or situation we can discuss this with you and refer on to other services if necessary. All information will therefore remain confidential within these stated limits, unless disclosure is essential to protect anyone involved from the risk of significant harm, or disclosure is required by law. Examples of this would be if your relative/spouse/friend or a family member, were shown to be at risk of physical violence or there was a disclosure of vulnerability or abuse. In such cases we would need to access the appropriate services in order to provide the necessary support and help required.

**What would happen if anyone was ill during the study period?**

We can rearrange, or delay, appointments if your relative/spouse/friend or their carer is unwell for short periods during the study. If however, illness or change of circumstance is over a longer duration we can discuss this with you. In these instances we understand that it may be necessary to halt involvement in the study. We would like, with your agreement, to keep and use any data gathered up to this point, as all data can help us understand everyday communication difficulties in semantic dementia.

**What are the risks or disadvantages of taking part?**

The main disadvantage of taking part in this research is the inconvenience and intrusion into the home. We will try to keep this to a minimum at all times and make appointment times to suit those concerned. If any aspect of the research is upsetting anyone we can stop. We can arrange for support from the speech therapist, or local neurology or mental health service, if anyone needs someone to talk to outside of the research project about the condition.

In the event that something does go wrong and anyone is harmed during the research there may be grounds for a legal action for compensation against the University of Manchester or participating NHS Trusts but the individual concerned may have to
pay their legal costs. The normal NHS complaints mechanisms will still be available to you and your relative.

**What are the benefits of taking part?**
We very much hope that taking part in this study will help all those involved understand this condition better and give tips on how to manage communication as best they can. It will also help others such as the person’s GP understand how their condition affects them. In broader terms we hope to find out more about semantic dementia so health services in this country and internationally, can provide better advice to people with this condition.

**What happens if the video camera is lost or broken?**
The video camera belongs to the University of Manchester. We understand that you/your relative/spouse/friend will take care of it but also that accidents can happen. If the camera is broken or lost, do not worry, you/your relative/spouse/friend would not be expected to pay for any damage or for it to be replaced. However, if it is lost any recordings on the camera would also be lost with it and the University would be unable to retrieve these.

**What will happen to the results of the research?**
Before we write up the final results we will visit you and your relative/spouse/friend at home to discuss these with you. We can talk about what the results mean and add any missing information. The results will form part of a Doctoral Thesis at the University of Manchester. The results will be written up for professional journals and other relevant information resources. We will make sure a copy of this is available for you, and the family, if you wish. We will also present the findings at professional conferences. No one will be identifiable in any of these documents as we change names, places and any other identifiable information. We hope this will help others understand semantic dementia better.

**What will happen to the video and audiotapes at the end of the study?**
Semantic dementia is a relatively rare condition. We would like the opportunity to retain the video clips after the end of the study for:

- Further research
- Conference presentations
- Small group research presentations
- Teaching

In order to be sure that we know how you would like us to use these recordings we would like to check with you whether you think your relative/spouse/friend would object to our using these:

- To use in further studies at the University of Manchester examining conversation in semantic dementia.
- To use selected video clips at conferences to illustrate the results of this study.
- To show other researchers interested in semantic dementia and conversation to demonstrate our findings.
- To teach speech and language therapists and other health and social care professionals and students in training for these professions about semantic dementia.

We would not use the videos outside of these purposes. All videos will be kept securely. There are specific sections on the consultee declaration form in order for you to indicate whether your relative/spouse/friend would agree or disagree to these uses. If you do NOT feel your relative/spouse/friend would agree to these uses, this will not affect your relative/spouse/friend’s ability to participate in the research project.

**Who has reviewed this study?**
This study has been reviewed by experts at the University of Manchester. It has been reviewed and given a favourable opinion by the North West 6 Greater Manchester South Research Ethics Committee.

**Who should I contact if I have a question or problem during the study?**
Please feel free to ask questions of any member of the research team at any time (see numbers on front sheet). If you have any unresolved concerns or complaints you can contact one of the University Research Practice and Governance Coordinators on 0161 275 7583 (email research-governance@manchester.ac.uk).

Thank you for taking the time to consider this study.
APPENDIX 8
Examples of Consent Forms

1) Participant consent.
2) Carer-participant consent.
3) Personal consultee declaration.
Sustaining everyday conversations for couples where one partner has semantic dementia

Please initial box

1) I confirm that I have read and understood the information sheet dated (version 3 – 11/07/13) for the above study.

2) I have had an opportunity to ask any questions and have had these answered.

3) I understand that my participation is voluntary and that I can withdraw at any time from the study without giving a reason, and without my care or legal rights being affected.

4) I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my research records.

5) I agree for my interviews to be audio-taped and transcribed.

6) I agree for videotaping of myself in conversation with my family members and for this to be transcribed.

7) I agree for anonymised quotations from the audio/video tapes to be used when reporting the research study.

8) I agree for the video clips to be retained for use in further studies at the University of Manchester examining communication in semantic dementia.

9) I agree for selected video clips to be shown at conferences to illustrate the results of this study.

10) I agree for video clips to be shown to other researchers interested in
semantic dementia and conversation to demonstrate the findings of this study.

11) I agree for video clips to be used to teach speech and language therapists and other health and social care professionals and students in training for these professions.

12) I agree for the principal investigator, Jacqueline Kindell, to discuss information about my medical history with the clinician responsible for the care of my semantic dementia.

13) I agree for the research team to notify my GP or any other health care professionals involved with the care or treatment of my semantic dementia.

14) If I have to leave the study early, due to ill health or change of circumstances I agree for the study team to retain and use any data gathered up to this point for the purposes of this research project.

15) I agree to take part in this study.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
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<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Name of Researcher</th>
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<tr>
<th>Date</th>
<th>Signature</th>
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</tbody>
</table>

For further information please contact: Jackie Kindell – Clinical Research Fellow
Copies kept: 1 copy for participant, 1 for research file
(Form E – 11/07/13 – V3)
**RESEARCH Participant Carer Consent Form**

**Sustaining everyday conversations for couples where one partner has semantic dementia (F)**

1) I confirm that I have read and understood the information sheet dated (version 3 - 11/07/13) for the above study.

2) I have had an opportunity to ask any questions and have had these answered.

3) I understand that my participation is voluntary and that I can withdraw at any time from the study without giving a reason, and without my relative/spouse/friend’s care or our legal rights being affected.

4) I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to our taking part in this research. I give permission for these individuals to have access to my research records.

5) I agree for my interviews to be audio-taped and transcribed.

6) I agree for videotaping of myself at home in conversation with my spouse/relative, and for this to be transcribed.

7) I agree for anonymised quotations from the audio/video tapes to be used when reporting the research study.

8) I agree for the video clips to be retained for use in further studies at the University of Manchester examining communication in semantic dementia.

9) I agree for selected video clips to be shown at conferences to illustrate the results of this study.

10) I agree for video clips to be shown to other researchers interested in semantic dementia and conversation to demonstrate the findings of this study.

11) I agree for video clips to be used to teach speech and language...
therapists and other health and social care professionals and students in training for these professions.

12) I understand that, with my relative/spouse/friend’s consent, their GP, or other clinician involved in the care or treatment of their semantic dementia, will be informed that we are taking part, and about the results of this study. I agree to this.

13) If I have to leave the study early, due to ill health or change of circumstances I agree for the study team to retain and use any data gathered up to this point for the purposes of this research project.

14) I agree to take part in this study.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Date</th>
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</table>

<table>
<thead>
<tr>
<th>Name of Researcher</th>
<th>Signature</th>
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<table>
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<tr>
<th>Date</th>
<th>Signature</th>
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</tbody>
</table>

For further information please contact:
Jackie Kindell – Clinical Research Fellow

Copies kept: 1 copy for participant, 1 for research file

Form F (11/07/13 – V3)
CONSULTEE DECLARATION FORM (G)
Sustaining everyday conversations for couples where one partner has semantic dementia.
Researchers: Jacqueline Kindell, John Keady and Ray Wilkinson

<table>
<thead>
<tr>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) I …………………………………………. have been consulted about ……………………………………………participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.</td>
</tr>
<tr>
<td>2) In my opinion he/she would have no objection to taking part in the above study.</td>
</tr>
<tr>
<td>3) I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.</td>
</tr>
<tr>
<td>4) I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from the University of Manchester, NHS Trust or from regulatory authorities, where it is relevant to their taking part in this research. I agree to these individuals to have access to his/her research record.</td>
</tr>
<tr>
<td>5) I agree for his/her GP, and other relevant clinician involved in the care or treatment of his/her semantic dementia, to be informed of their participation in the study.</td>
</tr>
<tr>
<td>6) I agree for the principal investigator, Jacqueline Kindell, to discuss information about ………………..medical history with the clinician responsible for the care of their semantic dementia.</td>
</tr>
<tr>
<td>7) I agree for interviews to be audio-taped and transcribed.</td>
</tr>
<tr>
<td>8) I agree for videotaping of conversation at home with a family member and for this to be transcribed.</td>
</tr>
<tr>
<td>9) I agree for anonymised quotations from the audio/video tapes to be used when reporting the research study.</td>
</tr>
</tbody>
</table>
10) I agree for the video clips to be retained for use in further studies at the University of Manchester examining communication in semantic dementia.

11) I agree for selected video clips to be shown at conferences to illustrate the results of this study.

11) I agree for video clips to be shown to other researchers interested in semantic dementia and conversation to demonstrate the findings of this study.

12) I agree for video clips to be used to teach speech and language therapists and other health and social care professionals and students in training for these professions.

13) If he/she has to leave the study early, due to ill health or change of circumstances, I agree for the study team to retain and use any data gathered up to this point for the purposes of this research project.

Name of Consultee ___________________________ Date _______________ Signature _______________

Relationship to participant: ___________________________________________________________

Researcher ___________________________ Date _______________ Signature _______________

For further information please contact: Jackie Kindell – Clinical Research Fellow

Copies kept: 1 copy for personal consultee, 1 for research file
Form G (11/07/13 V3)
APPENDIX 9

Recruitment Schedule

1. J. Kindell to give talks about research to variety of clinical groups/teams.

2. Clinicians asked to identify potential participants (information given about inclusion/exclusion criteria).

3. Clinicians have initial discussion with potential participants. A request for further information is sent to study team for those potential participants interested in the study.

4. J. Kindell to contact potential participants and visit to explain study – using verbal explanation, written information, pictures & ’show and tell’ where necessary.

5. Participants given time to consider if wish to take part and then contact made:
   a. If no, no further contact.
   b. If yes, visit to assess and facilitate consent.
   c. Use British Psychological Society (2008) “Conducting Research with People not having the Capacity to Consent to their Participation”.
   d. Personal consultee consulted as required.
   e. Consent recorded for carer and person with semantic dementia.
APPENDIX 10

Case Study One Peter and Joanna - Additional Information

CAPPCI Results – Pre- and Post-Therapy

Key to Scoring:
Frequency: 0 = never a problem, 1 = occasionally a problem, 2 = frequently a problem
Problem Severity: 0 = not a problem, 1 = a bit of a problem, 2 = a big problem

Table A10.1 – Peter and Joanna CAPPCI results

<table>
<thead>
<tr>
<th>Case Study One Peter</th>
<th>PRE Freq</th>
<th>PRE Prob</th>
<th>POST Freq</th>
<th>POST Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>INITIATION AND TURN TAKING</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Ability to initiate conversations</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>2 Failure to respond when next speaker</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3 Delay in responding</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4 Long pauses in the middle of turns</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5 Interrupting</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6 Failure to hand over conversational floor</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>7 Reliance on minimal acknowledgements</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOPIC MANAGEMENT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Ability to initiate new topics</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>9 Failure to orient partner to new topics</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>10 Ability to maintain topics</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11 Topics based on hallucinations</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>12 Repeated use of favourite topics</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>REPAIR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Ability to initiate repair on partner’s turn</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>14 Ability to initiate repairs on own errors</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>15 Ability after self-initiation to repair own errors without help</td>
<td>2</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>16 Ability to repair own turn when initiated by conversational partner</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>MEMORY AND ATTENTION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 Repeated questions and comments</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>18 Failure to remember family, friends or events discussed in conversation</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>19 Presence of abandoned turns</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20 Failure to retain instructions</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>LINGUISTIC ABILITIES</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 Failure in word retrieval</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>22 Production of circumlocutions</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Use of uncorrected semantic paraphasias</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Failure in comprehension</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Overuse of pronouns or proforms</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

**HIGH LEVEL LINGUISTIC ABILITIES**

| Ability to interpret non-literal meaning | 0 | 0 | 0 | 0 |
| Ability to make inferences | 2 | 2 | 2 | 1 |
| Ability to understand humour | 2 | 1 | 2 | 0 |
| Ability to use humour | 2 | 1 | 0 | 0 |

**ARTICULATION AND PROSODY**

| Impairment of articulation | 0 | 0 | 0 | 0 |
| Impairment of control of volume | 0 | 0 | 0 | 0 |
| Production of monotonous intonation | 0 | 0 | 0 | 0 |
| Ability to use prosody to stress words | 0 | 0 | 0 | 0 |

**FLUCTUATIONS**

| Fluctuation over the day | 0 | 0 | 0 | 0 |
| Fluctuation over the week/s | 0 | 0 | 0 | 0 |

Table A10.2 – Summary of video data - Peter and Joanna

<table>
<thead>
<tr>
<th>Pre-therapy Date</th>
<th>Length minutes</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>09/11/2012</td>
<td>2:49</td>
<td>After lunch sat at kitchen units 1:59pm</td>
</tr>
<tr>
<td>10/11/2012</td>
<td>2:45</td>
<td>Breakfast sat at kitchen units 10:03am</td>
</tr>
<tr>
<td>10/11/2012</td>
<td>7:05</td>
<td>Breakfast sat at kitchen units 10:13am</td>
</tr>
<tr>
<td>11/11/2012</td>
<td>17:31</td>
<td>Breakfast sat at kitchen table 10:25am</td>
</tr>
<tr>
<td>12/11/2012</td>
<td>20:35</td>
<td>Breakfast sat at kitchen units 10.25am</td>
</tr>
<tr>
<td>16/11/2012</td>
<td>15:27</td>
<td>Finished breakfast sat at kitchen units 10:41am</td>
</tr>
<tr>
<td>19/11/2012</td>
<td>22:47</td>
<td>Evening meal sat at kitchen table 9:17pm</td>
</tr>
<tr>
<td>21/11/2012</td>
<td>27:40</td>
<td>Breakfast sat at kitchen units 10.15pm</td>
</tr>
<tr>
<td>22/11/2012</td>
<td>12:02</td>
<td>Joanna ironing Peter sat down 7:36pm</td>
</tr>
<tr>
<td>30/11/2012</td>
<td>16:00</td>
<td>Eating lunch sat kitchen units 2:25pm</td>
</tr>
<tr>
<td>05/12/2012</td>
<td>9:53</td>
<td>Joanna preparing tea, both in kitchen 7:50pm</td>
</tr>
<tr>
<td>06/12/2012</td>
<td>15:19</td>
<td>Breakfast sat at kitchen units 10:31am</td>
</tr>
<tr>
<td>11/12/2012</td>
<td>17:14</td>
<td>Breakfast sat at kitchen units 10:28am</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post-therapy Date</th>
<th>Length minutes</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>18/08/13</td>
<td>23:48</td>
<td>Preparing &amp; eating lunch sat at kitchen units 1:23pm</td>
</tr>
<tr>
<td>29/08/13</td>
<td>14:33</td>
<td>Sitting on sofa in the lounge 6:17pm</td>
</tr>
<tr>
<td>02/09/13</td>
<td>5:24</td>
<td>Breakfast sat at Kitchen units 9:35am</td>
</tr>
</tbody>
</table>
Peter and Joanna - Further Examples of Conversation Analysis Data:

Extract 2) - Test question (V 11/11/12)
In this example Peter and Joanna are at breakfast. There is an array of jams on the table and Joanna asks Peter which one he wants:

001 J which tell me
002 P ((taps jar directly on the lid))
003 J tell me what it’s called what is it
004 P I don’t know hhh
005 J just said there’s blackcurrant ‘n apricot
007 P ah right ok
008 J so which one is that
009 P ((peers over))
010 J blackcurrant raspberry and apricot so
011 P which one do you think this one is apricot
012 P (.)
013 J hhh ((hands over jar and spoon))

In line 002 Peter indicates which type of jam he would like by tapping the jar. Rather than accept this nonverbal response, Joanna uses a test question “tell me what it’s called” (003 in yellow), thus pursuing the particular lexical item, with further test questions in 008 and 011. Joanna attempts to cue Peter by providing the correct word in a forced alternative choice (005 and 010). In 012 Peter provides the word.

Extract 4) - Comprehension difficulties (V 09/11/12)
Joanna is talking to Peter about a past family story they have often laughed about over the years.

001 J was the first time they tried to do Christmas
002 P and Vivienne cooked the turkey upside down
003 P ((looking down no reaction))
004 J and Dylan tried to carve it from that way do
005 P you remember
006 P Eee ye:ah ((looking down no reaction))
007 J it was chaos
008 P it was chaos ((fairly flat intonation))
009 J and that was before they had children
010 P oh did they ((looks up interested))
011 J their first xmas ((frowns at Peter))
012 P Oh right yes yes yes yes

Following Joanna’s introduction (001-002), Peter shows no reaction, so she continues. His reaction in 006 “hee ye:ah” does not sound convincing that he
remembers. His echo of her line in 008 shows he is listening but in 010, in green, Peter looks up appearing perplexed by Joanna’s comment. She clarifies this in line 011, but beyond agreeing he gives no other indication (such as laughing, expanding the topic) to show he genuinely understands the conversation. Thus, this familiar and often told family story is no longer provoking the expected interaction between them as it has done in the past and, in this way, serves to highlight a lack of connection.

Extract 6) - Repetitive questions (V 12/11/12)

At breakfast, Peter repeatedly asks a question he has already asked moments before (in green):

001 P Are we doing anything today
002 J what have we just been talking about what what
003 have we just been saying
004 P got to get my (1.0) boots on
Conversation about activities that day, then silence
037 P so what am I doing now
038 J having your breakfast
039 P oh
Conversation about the noticeboard there to remind him about the day’s events followed by silence
071 P ((looks at J))
072 J what what
073 P mm (8.0) shall I speak
074 J mm course you can speak
075 P (3.0) so what am I doing today
076 J ((stares)) (2.0) that’s the fourth time
077 you have asked me that
078 P oh
079 J do you realise that or do you no
080 P no I well er er (.). right ok I’ll
081 ((shrugs))
082 J no its fine Peter but we have gone through
082 this several times and I’ve now written it
083 down for you ((looking down)) mmm ((joint
eye contact))
085 P so what are we doing to\t\tomorrow
086 J ((sigh)) I don’t know

In this example Peter asks “are we doing anything today” in line 001, the fourth time he has asked this in eight minutes. Joanna exhibits her frustration at this in 002 with a complaint that they have just been talking about this. In 037 Peter asks “so what am I doing now”, a variation on the theme of the routine. Joanna informs Peter about
the notice board, but clearly this strategy is not working. In 073 Peter again tries to initiate some interaction with a pleading “*can I speak.*” However, in 075 he again asks “*so what am I doing today*”, leading to a complaint from Joanna in 076, “*that’s the fourth time.*” In 084 Peter tries again, this time with a slightly different question, as if he is aware at this point of the need to change. However, his limited repertoire is against him and he can only change the question from today to “*tomorrow*”. Joanna sighs in frustration. Peter’s questions in each instance are after a period of silence.
<table>
<thead>
<tr>
<th>Topics discussed in each session</th>
<th>Supported by:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7</strong> a) What is semantic dementia? Homework – written sheets: what makes you both feel secure or anxious in conversation?</td>
<td>Written sheet.</td>
</tr>
<tr>
<td><strong>8</strong> a) Why is conversation important? b) What makes you feel secure or anxious in conversation? c) ‘Accepting and adapting’ - practical, emotional, conversation changes. d) Introduction to viewing the videos. Homework – discuss services with family.</td>
<td>Written sheet. Information on services. Video.</td>
</tr>
<tr>
<td><strong>10</strong> a) Discussion - management of word finding: prioritising flow over accuracy, giving information (‘feeding Peter the line’) and moving the conversation forward. Homework – practice giving information</td>
<td>Video.</td>
</tr>
<tr>
<td><strong>11</strong> a) Revisit strategies ‘prioritising flow over accuracy’ and ‘feeding Peter the line’ - verbally or by using photographs, leaflets, memorabilia etc. Homework – gather photos for life story work</td>
<td>Written sheets. Modelling.</td>
</tr>
<tr>
<td><strong>12</strong> a) Supporting understanding supports memory. b) The importance of ‘show and tell’ and having a joint focus to support conversation. c) Developing life story resource.</td>
<td>Written sheets. Modelling.</td>
</tr>
<tr>
<td><strong>13</strong> a) Compiling life story resources: A5 books and miniature pocket summary resource. b) ‘Staged’ photographs to illustrate Peter’s interests. c) Discussion about test questions.</td>
<td>Life story resources.</td>
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<td><strong>14</strong> a) Continue with life story resource. b) Discussion of support services.</td>
<td>Life story resources.</td>
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<td><strong>16</strong> a) Revisit managing repetition. b) Practice using life story resources. c) Discussion of caregiver stress &amp; support.</td>
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<td><strong>17</strong> a) Discussion - managing behaviour, topics and issues likely to cause distress and knowing when to ‘back off’. Discussion – urgent need for additional support services.</td>
<td>Summary sheet.</td>
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Peter and Joanna - Sheets used in therapy

- **Sheet 1**: Semantic Dementia – Overview.
- **Sheet 2**: Living with Semantic Dementia – Some Common Questions.
- **Sheet 3**: Why is Conversation Important?
- **Sheet 4**: Security for the Person with Dementia.
- **Sheet 5**: Word Finding Difficulties – ‘Prioritising Flow over Accuracy.’
- **Sheet 6**: Stimulating Conversations – ‘Feeding the Line.’
- **Sheet 7**: Managing Repetition in Semantic Dementia.

Each printed over the following pages.
Sheet 1 - Semantic Dementia – Overview

Dementia is an umbrella term used to describe a range of conditions that can affect a variety of brain functions. These days most people have heard of Alzheimer’s disease and are aware of some of the features of this condition. However, there is less public awareness about other types of dementia, including a spectrum of conditions that often goes under the heading ‘frontotemporal dementia’.

One type of frontotemporal dementia is ‘semantic dementia’. This condition presents with communication difficulties. It can be hard to find out accurate information about semantic dementia as different terms may be used for the same condition, e.g. the condition may also be referred to as “the temporal variant of frontotemporal dementia” (because it affects the temporal lobes of the brain), “the semantic variant of primary progressive aphasia” (because it affects the communication systems of the brain) or in older leaflets and books as “Pick’s disease” (after the man who initially recognised such symptoms).

What is Semantic Dementia?

Semantic dementia is a condition where there is progressive damage to the temporal lobes of the brain. The temporal lobes store an individual’s general knowledge about the world that has been accumulated and learnt over the life span. This includes storage of the meaning of words, objects and concepts. This storage is called ‘semantic (i.e. meaning) memory’.

It is thought that the temporal lobes store and organise words and concepts in a hierarchical fashion. Thus, all ‘animals’ are linked and then broken down into smaller categories, e.g. ‘animals’ may include mammals, birds, fish, reptiles etc. Each category is further broken down into subdivisions, e.g. ‘mammals’ into: farm animals, wild animals, domestic animals etc. Words and concepts can be grouped in a variety of ways but in basic terms it might look something like this:

![Semantic Dementia Diagram]

- Animals
  - Mammal
    - Farm
      - sheep
    - wild
    - domestic
  - Bird
    - cow
    - squirrel
    - dog
Likewise, other concepts are organised into other such categories and subcategories, e.g. household objects, transport, tools, time, people we know etc.

This organisation of concepts is important for both finding words when talking and for understanding words when listening to others. This organisation helps the brain to do these tasks efficiently. It allows the brain to sort through material in an efficient manner, rather than randomly sorting through huge amounts of words, visual images and concepts. Thus, in many respects, it is thought that the temporal lobes of the brain organise information much like a computer would do, in order to find files of different information.

It is thought that in semantic dementia the organisation and storage of this conceptual knowledge is affected. For example the boundaries between categories
can become blurred. This makes it harder for the brain to sort through information both when trying to look for words when talking and trying to find the meaning of words when listening.

**How does this relate to Peter’s symptoms?**

Peter is experiencing the language difficulties that are typical of semantic dementia:

- Problems finding words when talking
- Difficulty understanding

This is because the store of words and concepts has been affected by the condition. Thus when asked to: “push down the toaster”, Peter may not know what to do because he is not able to sort through the important words quickly and efficiently enough, i.e. ‘push down’, ‘toaster’. As the boundaries between words similar in meaning are blurred, Peter may not be able to sort ‘toaster’ from other similar electrical items and he may look around the kitchen wondering what he is being asked to do. When this is repeated with pointing towards the toaster, he may then be able to understand.

When Peter is talking, because the word storage is now less organised, this makes it hard to find the right words when he needs them. This often leads to long pauses when he is unable to retrieve the word or he may choose the wrong word, often a related word, and this may be misleading. Thus, he may say “what time is it” when he actually means ‘what day is it’. It is common for words close in meaning to be mixed up, e.g. son and brother, train and boat etc.

**Are there any other symptoms?**

People with semantic dementia can become preoccupied with certain activities and routines. This may, in part, reflect their need to feel secure within concepts and activities they still understand and know, as such personally related concepts are thought to be retained longer. They may therefore enjoy a restricted range of hobbies or talk about a reduced range of topics. This is not necessarily because they are being difficult or have become ‘obsessive’ about such matters. It is more likely to be because other activities, or topics, have now become harder to understand and talk about. Many people with semantic dementia become reliant on a routine or become anxious if they do not know what they are doing that day or even what activity they are doing next. Again, it seems that knowing such things provides some security within an otherwise less secure world.

Therefore, for Peter personally related topics such as ‘tennis’ and ‘running’ have become important ‘anchors’ in his life and provide security for both activity and talking. We will explore these issues further over the coming weeks.
Sheet 2 - Living with Semantic Dementia – Some Common Questions

How is semantic dementia diagnosed?
There is not one test that can diagnose semantic dementia. Diagnosis is carried out by piecing together information from memory and language tests, the history of the problem(s), physical and laboratory examinations and brain scan results. This process involves examining the pattern and evolution of symptoms over time.

Why have we never heard of semantic dementia before?
It has been known for many years that there is a collection of dementia conditions that appear to present with difficulties with language and/or social skills, rather than starting with the more ‘typical’ pattern of forgetfulness. In older books these conditions were all labelled under the heading of Pick’s disease, named after the Czech Neurologist, who described such conditions back in the 1890’s.

Since the 1980’s and 1990’s there has been further research studying these conditions and, at this time, semantic dementia was identified as a clinical syndrome. The condition has a different profile of both difficulties and retained skills, than seen in other dementias such as Alzheimer’s disease.

Semantic dementia is often classified as a language presentation of frontotemporal dementia. When looking up the condition the different labels often make it hard to find accurate information. Sometimes leaflets collapse all the different types of frontotemporal dementia into one (the other conditions are the behavioural variant of frontotemporal dementia and nonfluent primary progressive aphasia). However, this can be misleading, as although there is some overlap in the conditions, in the mild to moderate stages individuals may have very different needs. It is also important to be aware at all times, that not all individuals develop all of the symptoms that may be described under a given condition.

In what way is semantic dementia different from Alzheimer’s disease?
In both conditions there is damage to the cells of the brain. However, the pattern of brain regions affected is different. Processes in the brain are regionally organised and this gives different patterns of difficulties and skills. The typical presentation of problems in Alzheimer’s disease is one of memory difficulty, more specifically, difficulty learning and retaining new information. This leads to problems with recent and short term memory and so individuals may quickly forget what they did earlier today, yesterday or last week. This can lead to the person becoming disorientated in time.

Semantic dementia presents with a different set of issues. Usually the earliest signs are with language skills because the condition affects the cells in the temporal lobes of the brain that are involved in understanding words and concepts (see associated sheet). This leads to problems understanding and finding words when talking. However, individuals with early semantic dementia often have a good memory for the passage of time and for day to day events, assuming they understand the topic/area under discussion. They also can often find their way about their local area with no difficulty very much later into the condition.
Sometimes my husband/wife can do very complicated tasks with no problem but fails with seemingly easy things – why is that?

One of the hallmarks of semantic dementia is the ‘juxtaposition’ of both skills and difficulties. Thus one carer remarked that her husband could drive long complicated journeys and find his way with no difficulty, yet could not ‘remember’ basic words such as ‘comb’. At times, this makes the condition seem very odd, or even that the person may not be trying as hard as they should. However, this is not the case. It is simply because certain parts of the brain are still working well and showing skills (e.g. finding your way), whilst the language areas of the brain are not working efficiently, giving the person their difficulties.

If she/he tried harder would he be able to remember the words?

No, the problem is not one of attention and concentration and so thinking harder does not make things any easier. Sometimes putting the person on the spot to think of an exact word can actually have the opposite effect because they become more frustrated and this can interfere with their thinking.

What exercises can we do to keep the brain going?

Currently no specific exercises have been advocated to help in semantic dementia, although many people very much enjoy Sudoku and word searches. Across the dementias there is evidence that keeping both physically and socially active as much as possible seems to help individuals live better with their dementia. This includes regular exercise, socialising with family and friends and attending activities in the community.

Do people with dementia have insight into their condition?

This is a complicated question to answer because ‘insight’ is not a single thing. Many people with semantic dementia are aware they have been given a diagnosis that affects their thinking and language abilities. They are often able to discuss this and the distress this causes them and those around them. They are often acutely aware when not being able to find a word and this can cause a great deal of frustration.

However, this does not always mean that they can put into place strategies or actions to change their situation or manage their symptoms, as they might have done with other illnesses in the past. In addition, the person may be less aware of the other changes in their social skills and behaviour. This can make conversations about the condition difficult as the person may not see the same picture as the caregiver sees and this can lead to disagreements. Often the person with semantic dementia may not be able to understand the ‘bigger picture’ as the carer does. If this is the case then such conversations and references to the person’s condition are best avoided, to avoid distress for both parties.

How do people with semantic dementia and their families adjust to living with this condition?

There is very little research evidence documenting how people learn to live with semantic dementia. It would appear from clinical experience that, in common with other types of dementia, that each individual and, each family, has their own unique way of doing this. For example, people refer to their condition in different ways and
make sense of what is happening to them in their own way. Equally caregivers vary in the way they cope with the condition.

We will be discussing this further over the next few weeks.
Sheet 3 - Why is Conversation Important? (Adapted from SPPARC)

Conversation is central to our lives. We use conversation all the time to develop and maintain friendships and relationships. Conversation lets us be part of the social world and we use it to let other people know what we think and how we feel.

How we talk to our partners, family, children, friends and colleagues reflects the different roles we take in life, and contributes to how we feel about ourselves. In this way conversation helps us develop and form our identity.

Whilst it is often popular to talk about human communication as a way of transferring information from one person to another, it is far more than that. It is through conversation that we express our identity and meet a variety of other emotional needs.

Needs and Security in Conversation

When we have no difficulty with communication we take for granted the complexities involved - the skills we have learnt over a life time. Conversation involves two or more people, taking turns in an organised and fine-tuned manner. Studies of conversation show that the process is collaborative, i.e. people closely attend to each other and help each other out if necessary. In normal everyday conversation there can be issues that threaten to break down the flow of the exchange. Such instances of ‘trouble’ in the conversation can include:

- Difficulty hearing the other person.
- Misunderstanding or not understanding the other person.
- Difficulty expressing oneself clearly, e.g. not being able to find the right words.
- Not understanding what is, and is not, relevant to the topic at hand.
In dementia these difficulties happen much more often than in normal conversation. This means the other party has to help out more or ‘scaffold the conversation’, to reduce any difficulties or unravel any trouble that occurs. This can sometimes make conversation frustrating for both the person with dementia and the carer.

Carers sometimes say they have to be a ‘mind-reader’ to get to the bottom of things. Sometimes for them conversation can feel one sided.

People with dementia on the other hand, find that conversation is no longer secure territory. It can be hard for them to find the right words, to understand and to play an active role. They may look frustrated or perplexed and this makes it hard to express identity and other emotional needs through talking.

Looking at ‘trouble’ and the associated ‘scaffolding’ strategies required in conversation, can help think about this process and help find ways to foster security and emotional needs in conversation.
Sheet 4 - Security for the Person with Dementia

For the person with dementia, security is often provided for them by the caregiver, their routine and the support network surrounding them. This enables them to feel safe and secure both physically and emotionally as they go about their daily life. Often people with semantic dementia feel secure, or happy, with the things they know and understand. This may include doing familiar tasks, or talking about familiar things. The person is likely to feel less secure when asked to do things out of their routine, or if things do not happen in the way, or order, they normally do. In part, this is because in semantic dementia conceptual knowledge is affected. This is our store of understanding of the world and how things, and people within it, work and behave. However, personally relevant information is thought to be more resistant to such damage and to be retained longer.

Together this means that individuals with this condition can often function very well within personally relevant activities, routines or topics of conversation, but at the same time find other activities, or topics of conversation, of a similar level of difficulty, more challenging.

Communication difficulties mean that the person may not fully understand what is said to them, or be able to retain this information over time. They may have difficulty finding the words they need when they are talking. Such difficulties may mean that the person has difficulty thinking through different pieces of information, to reason through issues in conversation and respond appropriately. Likewise, they may find it difficult to talk things through as they would have done before, to debate and resolve potentially problematic matters.

In such instances the person may become anxious, as they may not understand the current situation and how they should respond within it. The person may recognise they are in difficulty, e.g. that they are struggling with an everyday task they could do previously, or that they are not expressing themselves as well as they used to. At such times the person may show their insecurity by looking perplexed or anxious, asking more questions or becoming visibly frustrated. Depending on how they are feeling, the person may reject well intentioned offers of help or advice.

Developing sensitivity to such issues can help foster security and reduce anxiety and frustration. Each individual expresses such emotions in different ways but learning to spot the signs for the person concerned and provide the necessary reassurance at an early stage can help reduce tension for both the person with dementia and the caregiver.
Issues that may influence ‘security’ for Peter:

The following issues may influence Peter’s sense of security in conversation. Problems in these domains may make Peter anxious, perplexed or frustrated.

1) **Understanding** - Peter sometimes has difficulty with understanding what is said to him, particularly if the words are not everyday words, the topic is less familiar or involves multiple pieces of information.

2) **Retaining information** – Peter finds it difficult to retain information or things that are said to him. This is due to difficulties with verbal short term memory. This type of memory is heavily influenced by communication difficulties. So, for example, poor understanding often means information is not fully understood and cannot therefore be stored effectively by the brain. It is then more easily forgotten.

3) **Word finding** – Peter is very aware of his difficulties with finding words and finds this very frustrating.

There are also things that help foster a sense of security for Peter and these include:

1) **Routines and familiarity** - Peter has a number of activities or routines that he likes to do including going for a run, playing tennis, writing in his diary, doing Sudoku and his jobs around the house. Such activities foster a sense of security and achievement for him and he often refers to these activities when he is talking. These are therefore important activities to maintain for him.

2) **Familiar topics and stories** - Although Peter enjoys talking about his current life, there are particular stories, events and topics that seem to recur that have particular importance to him. He for example talks about meeting Joanna and falling in love, playing tennis from being a small boy and how proud he is of his sons and grandchildren. These are significant story lines or ‘life lines’ and again are important to maintain.

3) **Visual support** - Because of Peter’s difficulty with understanding and retaining information visual support for talking is becoming increasingly important. This includes showing him things on the IPAD or using photos, objects or leaflets to prompt memories. Thus, increasingly showing him, as well as telling him what you mean, is helpful.

Over the coming weeks we will explore these and, other issues, in conversation.
Sheet 5: Word Finding Difficulties – Prioritising Flow over Accuracy

Word finding difficulties are a common feature of semantic dementia. The person may know what they want to say but be unable to find the word. In some instances the person may use one word when they mean another, e.g. say ‘son’ when they mean ‘brother’. This can cause a considerable degree of frustration for both them and their family. In the early stages of the condition the person may be able to think around the target word and use another word or phrase and, therefore, ‘repair’ the breakdown in the conversation. This is referred to as a ‘self-repair’ and is common in normal everyday conversation for us all. However, sometimes for those with more significant word finding difficulty, the person is unable to self-repair because they are unable to find alternative words or phrases, leading to prolonged searching and frustration.

Conversation normally flows and when it halts, even for a few seconds, those involved become aware of ‘trouble’ within the conversation (which is why we are all very aware of silences!). During prolonged word finding searches the person with semantic dementia and the caregiver’s attention are immediately drawn to the trouble. This then highlights a lack of competency on the part of the person with semantic dementia, as they struggle to find the word. People with semantic dementia are often very aware of word finding difficulties, even when they are not aware of other aspects of their condition. At these times they feel a sense of failure in conversation, rather than a sense of achievement. Sometimes they start to apologise for their failings.

Carers are in a difficult position at such times. They want the person to be able to think for themselves and do not want to jump in too early. They also worry because some dementia information advises against ‘finishing the sentences’ of someone with dementia. It is important though, to also think about what would normally happen in everyday conversation. While it appears that ‘self-repair’ is the first preference in normal conversation, when we are unable to self-repair and are still struggling, then ‘other repair’ is the normal sequence of events:

A  “what’s the name of that woman we used to work with…with the grey hair…oh…you know…err…desk at the end in finance…oh er…
B  “Oh you mean Sandra…started after I started…”
A  “Yes Sandra…well…last week…..etc…etc.

In this way when A is struggling to find a name, it is quite normal for B to give the word. In this way the conversational trouble is evident but it does not last too long and the conversation flows forward.

Carers often worry about giving the person with dementia the word, because they worry that the person may find this insulting, or that it may mean that they are less able to think for themselves in the future. Interestingly though, giving someone the word often leads to more and not less conversation, as the conversation flows forward giving more stimulation of different topics and ideas. In the above example the ‘trouble’ is dealt with and we move forward to hear the story about ‘Sandra’.
How does this relate to Peter?

In the past Peter has often been able to ‘self-repair’ his own difficulties with finding words, for example by thinking harder or talking around the word. However, as his word finding problems have become more prominent, he is now often not able to do this for himself and he is becoming reliant on others to repair the breakdown and restore the flow of the conversation. Peter is very aware of his word finding difficulties, often becoming frustrated and saying “it’s my memory problem” or apologising when he is unable to talk fluently. At other times Peter uses one word, when it is clear from the context that he means another.

At this stage of his condition prioritising flow over accuracy is probably more important than Peter being able to find the word, or the correct word, for himself. By giving a word when he is struggling, the flow of the conversation is restored and this reinforces a sense of achievement rather than a sense of failure.

We found by looking at our videos that helping Peter with the words actually led to more and not less conversation as the topic was able to move forward, rather than get stuck on one word or issue. Developing a different set of strategies to manage the problems is, as we have talked about, part of adapting to the changing condition.

The following strategies may be of help:

For word finding difficulties:

1. Give Peter time to think to see if he can get the word himself.

2. If he is beginning to struggle and the word is obvious, say the word, in a natural way: e.g. “oh you mean x.”

3. If the word is not obvious you may need to guess: e.g. “do you mean y?”

4. See if Peter can show you or take you to what he is talking about, e.g. “can you show me what you mean?” He might be able in such instances to get an object, photo, use a gesture or take you to what he is talking about.

5. If you are unable to get the word and the frustration is rising, use a ‘give in gracefully’ phrase: e.g. “we’re not getting this are we…don’t think about it now and I’m sure it will come back to you later.” You may need to distract Peter on to another topic or task to diffuse the matter. This is less about ‘giving in’ but more about managing frustration for both parties.

For word errors:

1. If you know Peter has used one word when he means another, avoid overtly correcting him. Instead respond as though he said the correct word while using the right word in your reply. So if Peter means ‘brother’ but says ‘son’
respond by saying “oh yes your brother is coming next week isn’t he.” In this way you give the right information but in an indirect manner. This is called an embedded correction.

2. Peter may use a vague word, such as ‘him’ or ‘that place’. Again in such instances if it is obvious who, or where, he is talking about, use that in your response. So if Peter says “he was there”, respond by saying “Harvey was at golf was he?”

3. Carers of people with semantic dementia become very good at ‘getting the general gist’ of a conversation while not getting to the bottom of every detail of who, what and where etc. This is not being patronising, it means helping out where you can, but accepting the level of difficulties and avoiding frustration for both parties. This helps Peter keep as much flow in his talking as possible.

4. Sometimes when Peter first starts a conversation or topic it may not be immediately obvious who or what he is referring to. It’s ok to let him talk for a bit before you get the gist, you could try something like “tell me more about this?”
Families of people with semantic dementia often say that the person with semantic dementia does not start conversation up as much as they used to, or that they talk about a narrower range of topics when they do. It is therefore often left to families to start up topics and try to stimulate conversation and make connections. In the earlier stage of the condition this is often done by asking questions:

- What did you do today?
- Who was at the club when you went?

However, as the condition progresses if the person has word finding difficulties then they may not be able to find the words to answer questions such as these. Often such questions require specific words or the names of people or places. Sometimes then, this puts them ‘on the spot’. In such instances therefore, such questions can feel like ‘test questions’ to the person with dementia. When they fail to find the word, they get frustrated and feel a sense of failure. They may apologise they cannot get things right.

As Peter’s word finding problems have got worse, starting topics can have exactly these challenges. Joanna has identified that the way round this is to “feed Peter the line”. In this way, the topic opener has the information embedded into it. This stimulates Peter to get involved in the conversation but gives him some of the key information already. This is more likely to lead to successful conversations. Here some examples of test questions and alternatively “feeding the line”:

<table>
<thead>
<tr>
<th>Test question</th>
<th>Feeding the line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who did you go to tennis with then?</td>
<td>So you went to tennis with Roger then eh?</td>
</tr>
<tr>
<td>Where are we going tomorrow?</td>
<td>We’re off to Leeds tomorrow aren’t we?</td>
</tr>
<tr>
<td>Whose birthday is it next week?</td>
<td>It’s Stacey’s birthday next week, yeah?</td>
</tr>
<tr>
<td>What did you get up to on holiday dad?</td>
<td>I hear the beach was lovely on holiday?</td>
</tr>
<tr>
<td>Where do you go on Friday?</td>
<td>So singing on a Friday’s always good then?</td>
</tr>
</tbody>
</table>

We have discussed other ways of starting or focussing on a conversation: using the IPAD to show photos or videos, looking at leaflets collected on recent trips out, looking at the life story book, getting out old photos or old objects. This works because you can both see the focus of the conversation and this leads to less pressure on both parties.
Caregivers report two common challenges related to repetition in semantic dementia:

1) Repetitive questions about the daily routine, such as asking what will happen that day or what time a certain activity will happen.

2) Talking about the same topics or areas of interest, such as telling the same stories over again.

These difficulties are frustrating for caregivers and it can be extremely difficult to be patient when you have been asked the same question over and over in a short space of time and provided the same answer, only to be asked it again moments later.

In contrast, the person with semantic dementia is often unaware they have asked the question before and can be baffled or upset when their spouse or relative becomes frustrated with them. They may become anxious if their question is not answered. In semantic dementia repetitive questions appear most often in relation to time or the daily routine. This seems to be subtly different to Alzheimer’s disease. Some researchers think people with semantic dementia cling on to this kind of knowledge because other things cease to make sense. Information about time, or the routine, become ‘landmarks or beacons’ that help guide or reassure them.

Likewise, people with semantic dementia often enjoy telling certain stories or recalling certain events. To them such events are very important, yet spouses/relatives have often heard these stories many times.

Carers develop their own ways to manage such issues but there are common threads. Carers often say that getting annoyed, or telling the person that they have already asked that question, or told that story, does not seem to help. However, they also say that it is extremely difficult to hide any rising frustration, with even the most patient of carers commenting that it is likely to show in their tone of voice!

This is why it is extremely important that carers think about their own needs too. Having time to do other things and unwind from the stresses of caring provides space to recharge emotional batteries. In this way taking time out, while the person attends day care or dementia clubs, is not only of benefit to the carer, it can also be of benefit to the person with dementia. Carers often feel guilty about this, however there is good evidence that retaining some interests outside of the caring experience can help carers cope better.

Written reminders can sometimes help with repetition. However, as the condition progresses the person may only find such notes helpful if they are right in front of them. They may not remember to look on a calendar or in a diary and if they do, they may then still ask the question when the diary is shut or they have walked away from the calendar.
Thinking about Peter:

When we looked through the videos and talked about this area, there were two areas that we thought were important, which seem to have different functions for Peter, and therefore seem to need different responses.

Questions like “what are we doing to do today/tomorrow?”

When we analysed the videos Peter most often asked this question after there has been gap in the conversation. He appeared to try and use this therefore to initiate a conversation, as well as seek information. At these times he appeared to be aware of the need to strike up a conversation but lacked the social, or topic repertoire, needed to do this appropriately. He therefore used something he knew well, which was a question about the day ahead, or even the day after that. Joanna and I discussed various strategies to manage this including:

1) **Avoiding the question in the first place.**
An example of this would be to have the TV or radio on during mealtimes so that any conversation that Peter does start up might be about what is on the news etc. Other examples would be to use the IPAD to show short videos, photos or his life story books to fill the conversation.

2) **Answering and then distracting.**
It is reasonable on the first occasion a question is asked, to answer it with the necessary detail one might use in a normal conversation. However, with subsequent questions, treating them less as a need for information but more as a need to start up a conversation might divert some of the rising frustration for both Peter and Joanna. So, rather than go through all the details of “what are we doing today” each time it is asked, another option may be to provide a shorter answer, e.g. “we’re going shopping” and then distract Peter on to another topic (either verbally, or showing him something on the IPAD, a leaflet etc.). It is not unkind or patronising not to answer the question in detail, it is simply that repeating the same information may not necessarily help Peter and that going over the same question repeatedly is frustrating for Joanna.

3) **Simple written prompts directly in front of Peter.**
It may help to write the answer to any questions on a piece of paper and then put it out directly in front of Peter, e.g. Tennis – Roger – 2 O’clock.

4) **Sticking to today**
It is entirely reasonable to want to take one day at a time and avoid questions about ‘tomorrow’ until at least the night before. Many carers use something like “let’s get today out of the way first” to avoid such questions.
**Telling the same stories**

Peter, like many people with semantic dementia, talks about a reduced range of topics. However, when he does strike up on one of the ‘stories’ that are important to him he becomes very animated and enjoys the conversation. He may not be aware that the other person has heard the story before or that it is not appropriate to introduce the topic at that point in the conversation.

Again some researchers think that this relates to the person trying to hold onto what they still know and understand. This is most often personally related topics that are important to their identity. Therefore, whilst such conversational topics may have little value in terms of new information exchange, they may provide other therapeutic value to the person with semantic dementia, which is about keeping them in touch with themselves and their identity.

This is part of the role of the life story books, i.e. to keep Peter connected to important memories or stories that have played a role in his life, including those stories and experiences he shares with family and friends. The books are structured so he can look through them himself or show them to others to stimulate conversations about these things.
Table A10.4 - Codes used to analyse conversation
J= Joanna, P=Peter

<table>
<thead>
<tr>
<th>Code - Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>KRE - Known Response Elicitor</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Joanna asking questions where answer known or prompts/cues to facilitate word or information.  
**Gold standard** = where elicitor is used + response given + third turn indicating a ‘yes’ or ‘no’ or equivalent to indicate that this is either correct or incorrect.  
**Silver standard** = where elicitor is used + response given BUT there is no third turn indicating whether the response was correct or not.  
Some overlap with OER - if Peter is required to supply a particular word or idea code as KRE. In strings of KRE - count as separate if Peter makes an utterance between, or if format changes in Joanna’s repetition.  
Where are we going from?  
Where is the station?  
How are we getting to Sheffield?  
P - What are we doing today?  
J - You tell me what we are doing today?  
CODE as KRE | |
| **OER - Orientating to error or repetition** | |
| Joanna comments Peter’s interactional performance is falling short of that required in the interaction:  
1. Direct comments about his repetition.  
2. Direct comments that he is not making sense.  
3. Rejecting Peter’s response.  
- Use of ‘no’ or other equivalent negative.  
- Shaking of the head instead of ‘no.’  
- Repeating back information with a questioning tone or incredulity.  
- Laughing (not shared laughter).  
4. Corrections on his Peter’s talk.  
Does not include comments on behaviour.  
In strings of OER - count as separate if Peter replies between, Joanna repeats with a different format, or if each of Joanna’s utterances has a different function.  
I’ve already told you…  
That doesn’t make any sense…  
We don’t go down the road to x station do we?  
You don’t mean a glass of wine do you?  
A glass of ↑wine? | |
| **OOD - Orientating to own performance** | |
| Comments from Peter indicating he is aware his interactional performance falls short of what is required at that point in the interaction including:  
- Aware in difficulty.  
- Unsure what to do next.  
- Asking for assistance or feedback.  
- Apologies about performance.  
Not included are general apologies for broader relationship issues & apologies for arguments, changes in life.  
I should know that…  
Oh sugar…(or other expletive commenting).  
Tell me?  
Have I got it right?  
Sorry (about speech). | |
Peter and Joanna – Further Examples of Conversation Analysis Data (Post-Therapy)

Extract 8) - test question answered quickly (V 09/08/13)

001 J can you remember what happened last time you should have gone with Ian
002 P ((blank look))
004 J ↑ no last time Ian was so busy because of his decorating he forgot to come
006 P a:h I’ll tell him hhhh

In 001 Joanna uses a test question but when Peter does not appear to remember, there is no attempt to prompt him, instead she gives the information. He responds to this in a good humoured way in 006 appearing to mean he’ll tell his friend off.

Extract 9) – the written word supporting talk (I 25/10/13)

Peter talks about one of his most important achievements in tennis, in free flowing conversation he is often observed to struggle for the name ‘Brentford’, here however, he reads it fluently; the life story book, thus supporting the target word:

001 P look
002 J what does that say
004 J ↑ oh that’s the picture ↑ isn’t it
005 P yeah yeah won a cup at Brentford ((reading text))
006 P that ((pointing at cup in the photo))

Extract 10) – the written word supporting talk (I 25/10/13)

The written word helps support both of us with names and information, so that Peter is able to tell me about some very good friends of theirs. After reading the statement about his friend Mike, Peter’s tone is appropriately sad, indicating he understands and feels this statement, as Mike was a good friend:

001 P ah ↑ Pamela ((reading text))
002 J ah from Huddersfield ((reading text))
003 P yeah Mike has passed away ((reading text))
004 ↓ ye:ah ((said with sadness))
005 J ↓ ah ((reflecting sadness))
APPENDIX 11

Case Study 2 Sarah and Reg - Additional Information

CAPPCI Results (Pre-therapy)

Key to Scoring:
**Frequency** 0 = never a problem, 1 = occasionally a problem, 2 = frequently a problem
**Problem Severity** 0 = not a problem, 1 = a bit of a problem, 2 = a big problem

Table A11.1 - Sarah CAPPCI results

<table>
<thead>
<tr>
<th>Case study 2 Sarah</th>
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<td><strong>INITIATION AND TURN TAKING</strong></td>
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<td>1 Ability to initiate conversations</td>
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<tr>
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Table A11.2 – Summary of video data - Sarah and Reg

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| 14/01/13 | 12:02  | 11:48am – waiting for carer  
Transcribed: 5:00-12:02 |
| 16/01/13 | 7:50   | 11.32am – waiting for carer |
| 18/01/13 | 6:44   | 12.12am – talking about doctor  
All transcribed |

<table>
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<tr>
<th>Set 2</th>
<th>Length</th>
<th>Comments</th>
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</table>
| 05/02/13 | 9:03   | 15.23pm – Sarah watching TV  
Transcribed: 5:28-9:03 |
| 09/02/13 | 9:04   | 16:48pm – Some talk about dementia, problems sleeping  
Transcribed: 0-5.35 |
| 11/02/13 | 7:09   | 17.08pm – Sarah asking Reg about her dementia at start, watching TV |
| 13/02/13 | 20:07  | 11.52am – Talk about weather  
Transcribed: 4.53-10.44 |

<table>
<thead>
<tr>
<th>Set 3</th>
<th>Length</th>
<th>Comments</th>
</tr>
</thead>
</table>
| 19/02/13 | 15.55  | 17.06pm – Just come in from day care  
Transcribed: 0-5.07 |
| 21/02/13 | ---    | Camera not working properly, not useable |
| 22/02/13 | 7:31   | 19:11pm – Watching the TV in the evening (TV loud)  
All transcribed |
| 23/03/13 | 1:25:00| 18:12pm – Watching TV in the evening TV loud |

Total video: 3:00:25 hours  
Total transcribed: 41:25 minutes
Sarah and Reg – Additional Examples of Conversation Analysis Data

Extract 11) - Lack of conversation (V 12/01/13)

Sarah and Reg are waiting for the carer. There are 5 instances of minimal responses (in yellow) from Sarah, i.e. monosyllabic responses, low in volume and accompanied by a lack of eye contact, thus conveying minimal participation in the interaction.

There are two other responses from Sarah (highlighted in green), where she looks to Reg, addresses his question briefly but she does not elaborate on her response.

001 R Suzanne will fetch us out take
002 us out maybe somewhere for a meal an ride
003 round for you you can say you’ve been out
004 then (2) alright
005 S mmm °yeah° ((no eye contact))
006 R now you didn’t sleep very well last night did
007 you
008 S I don’t know ((looks at Reg))
009 R you was up and down all night long saying
010 that you couldn’t sleep
011 S mmm ((no eye contact))
012 R I thought you probably would’ve wanted to
013 stop in bed a bit longer this morning
014 S mmm ((no eye contact))
015 R [but] you was up at half past seven and I
016 thought you might have wanted to have a
017 little sleep but you seemed to be awake again
018 now
019 S m ((no eye contact))
020 R do you feel tired
021 S not now ((looks at Reg))
022 R but seeing that you was up and down all
023 through the night and you didn’t sleep at all
024 you said
025 S mmm ((no eye contact))
Extract 13) - Direct reported speech (V 23/04/13)

Here I present another example of a recurring topic, taken from a video of us all together and here Sarah acts out the scenario around her getting her first job. This story is one that recurred very often in our encounters and one Reg reports Sarah often tells. The direct reported speech is in bold.

001 S Yeah she said I can remember this
002 ((pointing)) me mum was going to work
003 she said right love ((pointing)) there’s
004 a place down the road ((gesture that
005 way)) where we lived then which was the
006 place
007 J ((nod))
008 S go and see if they’ve got a job there
009 love ((pointing away))
010 J right
011 S I’m off to work now said °ok mum° when
012 I was off school °ok° anyway I can
013 remember this and I went in the place
014 and er I said I’ve never machined
015 °before but have you got a job she
016 said ↑yes we’ll take you on ↑board love
017 J hhh
018 S now in’t it funny I can remember that

Sarah acts out her mum’s talk in lines 003-004 and 008-009 and she accompanies this with pointing, as her mum would have done at the time. Her speech becomes quieter in lines 011-012 as she acts out what she would have said to her mum, displaying a timid quality to her talk, i.e. “°ok mum°”. In lines 014-015 Sarah acts out her own speech to the woman in the factory, again her intonation displays a timid aspect with falling intonation and extension of the vowel in “°before°”. The woman’s response in line 016 is positive and this is clear in Sarah’s louder volume and repeated rising intonation.
Extract 14) - Living with repetitive questions (V 18/01/13)
Sarah and Reg are waiting for the support worker to call and Sarah is seen to repetitively ask if they are going out and at what time the worker will call (in green) and each time Reg answers with patience. The duration of this whole extract is 6:44 minutes.

001 S are we going now
002 R yes but I’ve got we’re not doing what we
003 ↑thought

019 S oh is she gonna is she coming in a minute then
020 R no it will be dinner time because she’s running
021 late

046 S so what time will she be coming now
047 R well obviously with it snowing and being held
048 up at this lady’s house
049 S mm
050 R it’s hard to say exactly what time she’ll be
051 coming it’ll be after 12

079 S so what time she comin’ ↑twelve
080 R bout well she should normally be here for
081 twelve but it might be a little bit later

099 S why what time is she coming
098 R who
099 S the girl
100 R she’s coming between twelve round about twelve
101 could be a little bit after

170 S what time’s she comin;
171 R between 12 and half past
Extract 17) - Parties at our house (V 23/4/13)

Here Sarah is looking at her life story book with Jackie and her responses are minimal or quiet in volume (in green).

Sarah reads the word “parties” (003) and looks at the photos, but I am unable to encourage her to talk about these events. For example, “so parties with the girls” (006) and “these look good” (009) are both met with minimal acknowledgements, e.g. “m” (007); “ye-” (010) with considerable pauses in the conversation (008 and 011). When asked about getting dressed up for parties (015-016), despite the pictures clearly indicating this is the case, Sarah appears unsure and has to ask Reg: “I did didn’t I” (017). Therefore, in this instance despite the pictures, written cues and my cues “you look like you’re all dressed there” (012) this does not cue any memories, or any conversation, from Sarah.
DVD Cover – Case Study Two - Front and Back

Figure A11.1 – DVD cover with Sarah, Reg and family (blurred for anonymity)

Life Story Work is a way to make connections with people with dementia. This can be through photographs, objects or music to spark off meaningful connections with the person with dementia.

When people have difficulty with conversation remembering events from their life, music maybe the best way to make connections. Here we have used music and memories in a DVD to spark off engaging and personally related memories. In this DVD we see Mrs Jones’s love of music and singing. She’s a great singer and we can see the pleasure this brings her and the appreciation of her her family here.

We hope she will enjoy watching this from time to time.
Sarah and Reg - Additional Examples of Conversation Analysis Data (Post-Therapy)

Extract 20 - Interaction arising from lyrics (V 12/11/13)
Here Harriet and Sarah are singing to ‘the Lady in Red’ (M = music). In line 007 Sarah responds with a “thank you”, as though the lyrics Harriet has been singing are a compliment directed at Sarah. The effect is humorous and also indicates Sarah is processing the meaning of the words.

001 M [I've never seen you looking so gorgeous]
002 H [I've never seen you looking so gorgeous]
003 S [((clicking fingers))]  
004 M [as you did tonight]  
005 H [as you did tonight]  
006 S [((eye contact, smiling))]  
007 S oh thank you

Extract 21) - Making up own lyrics (V 22/11/13)
Sarah would sometimes make up her own lyrics, for example, in this extract again from Tina Turner, Sarah is singing in tune to the music, but with her own words, telling Harriet that she loves her (lines 003 and 006).

001 S better than all the rest hhh  
002 M [((music still playing))]  
003 S [ah ah I love you any time of day]  
004 H [((kisses S))]  
005 M [((music still playing))]  
006 S [I can’t stay awake I love you so oh oh oh o:]  
007 H [((kisses S))]  
008 S oh lovely thank you

In response to Sarah’s singing, Harriet kisses Sarah twice (004 and 007) and Sarah responds with a positive assessment of this “lovely thank you” (008).
Extract 24) - Embodied connections, ‘cheek to cheek’ (V 22/11/13)
In this example ‘The Lady in Red’ is playing and Chris De Burgh (M) is singing about dancing “cheek to cheek” (001). Harriet and Sarah sing along. Harriet then offers Sarah her cheek; they touch cheeks, making an affectionate connection.

001 M [cheek to cheek]
002 H [cheek to cheek] ((offers cheek...)
004 S [cheek to cheek]
005 H [((touch cheeks))]
006 S [((touch cheeks))]
Extract 29) - Embodied performance 2 (V 06/01/14)

While watching Cilla Black, ‘You are my World’, Sarah seems to particularly respond to the distinctive beat within the song.

001 M  As the trees reach for the sun above
002  [((distinctive beats))]
003 S  [((claps and moves head))]

Here in line 003, as she often does to this song, she claps and moves in time to the beat of the song.

Extract 30) - Embodied performance 3 (V 06/01/14)

Sarah is watching a very old song on the DVD, ‘I like a nice cup of tea’. Sarah taps in time to the music before joining in at line 004, signalling the important “nice cup of tea” with an emphatic point.

001 M  [And at alf past eleven well my idea of eaven]
002 S  [((tapping in time to music)).................... . . .]
003 M  [is a nice cup o' tea]
004 S  [((point)) cup of tea]
Extract 32) - Audience reaction 2 (V 06/01/14)

I comment on Sarah’s voice and she is very pleased with this.

001 J   lovely voice
002 S   ((looks at Jackie as if to say ‘pardon?’))
003 J   lovely voice
004 S   thank you ((looks at Jackie smiling)) °thank you°

Extract 33) - Audience reaction 3 (22/11/13)

Reg can often be heard to encourage Sarah with a “go on”, here in line 002 when singing to ‘Pretty Woman’.

001 S   ((looks to Jackie and smiles moving to music))
002 R   that’s it Sarah go on Sarah
003 S   go go go
004 M   [pretty woman]
005 S   [pretty woman]
APPENDIX 12

Case Study 3 Doug and Karina - Additional Information

CAPPCI Results (Pre-therapy)

Key to Scoring::
Frequency 0 = never a problem, 1 = occasionally a problem, 2 = frequently a problem
Problem Severity 0 = not a problem, 1 = a bit of a problem, 2 = a big problem

Table A12.1 – Doug and Karina CAPPCI results

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Table A12.2 – Summary of Video Data - Doug and Karina

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<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/07/13</td>
<td>52:35</td>
<td>Doug, Karina and Jackie all chatting in lounge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Video illustrates Doug’s performance skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All transcribed</td>
</tr>
<tr>
<td>24/08/13</td>
<td>6:05</td>
<td>Doug and Karina on own in lounge talking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Doug far less upbeat than when I am present</td>
</tr>
<tr>
<td>26/08/13</td>
<td>1:06</td>
<td>Doug and Karina in lounge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Karina encouraging Doug to drink his coffee</td>
</tr>
<tr>
<td>26/08/13</td>
<td>0:50</td>
<td>Doug and Karina in bathroom</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Karina prompting Doug to shave</td>
</tr>
<tr>
<td>26/08/13</td>
<td>1:07</td>
<td>Doug and Karina in bathroom</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Karina prompting Doug to shave</td>
</tr>
<tr>
<td>30/08/13</td>
<td>0:29</td>
<td>Doug and Karina in the hall</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Karina prompting Doug to put his slippers on</td>
</tr>
<tr>
<td>24/10/13</td>
<td>40:19</td>
<td>Doug, Karina and Jackie all in the lounge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Doug and Karina looking through life story book</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All transcribed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total video</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9:37 minutes – as couple</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1:32 hrs – couple + researcher (all transcribed)</td>
</tr>
</tbody>
</table>
Doug and Karina - Additional Examples of Conversation Analysis Data

Extract 39) - Performance (V 12/07/13)
Here Karina had been talking about a worker at the respite care home who always hugs him, I tease Doug about this and he breaks into song (singing in bold text). He abruptly ends this with a clap, says “oh sorry” (spoken not sung) and sits still with his arms folded, looking up to indicate this abrupt finish:

001 J So who’s this woman you’re hugging Doug
002 D hhhhh ((head back))
003 J who’s that (.) not your wife
004 D [no]
005 K [no]
006 D I’ll see you ((hand out shaking)) when you’re in the in the rain ((extensive shaking all over)
007 with arms moving up over head))((sudden clap))
008 oh sorry ((suddenly sits still with arms folded
009 and looks up))
010
011 J hhhh

Extract 40) - Life story book – failure to recognise pictures (V 24/10/13)
Here Doug and Karina are looking through Doug’s book. This is one of the many examples where he fails to recognise himself – here in his twenties even though it has this written underneath. Doug at first thinks it is Karina and is sure it is not him, displaying surprise when told this is the case.

001 K who’s that
002 D n’you here
003 K me it’s not me
004 D it’s not me ((looking closer))
005 K it is you
006 D [hnnn] ((looks at Jackie))
007 J [it’s you] it says me in my twenties ((reading words))
Extract 43) - The Navy 2 (V 24/10/13)

In this extract Karina was showing Doug a picture of boats and a medal and asking him about his time in the Navy in Java. He used the word ‘battle’ (003 in green) which appeared to be consistent with fighting pirates (004).

001 K  yes you were in Java can you remember anything
002  about Java
003 D  sim pre :brul a battle
004 K  when you were fighting the pirates in Java
005 D  was it the lies
006 K  I don’t know

Extract 44) - The Navy 3 (V 24/10/13)

In this extract Doug appeared particularly interested in the pictures of ships and pointed to the page. His speech was hard to follow but the word “furrie” (001 in yellow) could be a paraphasic error for ‘ferries’:

001 D  that’s the furries on ((pointing to page))
002 K  there’s some of your ships yes
003 D  those are the ones that are prenston prenston
004 K  and we’ve got some of the cap ((points to head)) things haven’t we for them
005 D  yes that’s crass crass
APPENDIX 13

Case Study 4 Ruby and Brian - Additional Information

CAPPCI RESULTS

Key to Scoring:
Frequency 0 = never a problem, 1 = occasionally a problem, 2 = frequently a Problem
Problem Severity 0 = not a problem, 1 = a bit of a problem, 2 = a big problem

Table A13.1 - Ruby and Brian CAPPCI results

<table>
<thead>
<tr>
<th>Case Study Four - Ruby</th>
<th>PRE Freq</th>
<th>PRE Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>INITIATION AND TURN TAKING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Ability to initiate conversations</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2 Failure to respond when selected as next speaker</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3 Delay in responding when selected as next speaker</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4 Production of long pauses in the middle of turns</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>5 Violations of conversational partner’s turns</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6 Failure to hand over conversational floor</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>7 Reliance on minimal acknowledgements</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOPIC MANAGEMENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Ability to initiate new topics</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>9 Failure to orient conversational partner to new topics</td>
<td>0??</td>
<td>0</td>
</tr>
<tr>
<td>10 Ability to maintain topics</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11 Presence of topics based on hallucinations or delusions</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>12 Repeated use of favourite topics</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>REPAIR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Ability to initiate repair on conversational partner’s turn</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>14 Ability to initiate repairs on own errors</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>15 Ability after self-initiation to repair own errors without help</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>16 Ability to repair own turn when initiated by partner</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>MEMORY AND ATTENTION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 Presence of repeated questions and comments</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>18 Failure to remember family, friends or events in conversation</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>19 Presence of abandoned turns</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20 Failure to retain instructions</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>LINGUISTIC ABILITIES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 Failure in word retrieval</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>22 Production of circumlocutions</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>23 Use of uncorrected semantic paraphasias</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>24 Failure in comprehension</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>25 Overuse of pronouns or proforms</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>HIGH LEVEL LINGUISTIC ABILITIES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>26 Ability to interpret non-literal meaning</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>27 Ability to make inferences</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>28 Ability to understand humour</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>29 Ability to use humour</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ARTICULATION AND PROSODY</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>30 Impairment of articulation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>31 Impairment of control of volume</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>32 Production of monotonous intonation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>33 Ability to use prosody to stress words</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FLUCTUATIONS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>34 Fluctuation of communication abilities over the day</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>35 Fluctuation of communication abilities over the week/s</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table A13.2 - Audio and Video Data Used to examine conversation - Ruby and Brian

<table>
<thead>
<tr>
<th>Date</th>
<th>Length</th>
<th>Format and comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>15/11/13</td>
<td>1:31:29</td>
<td>Audio data, Ruby, Brian and Jackie present life story interview Transcribed</td>
</tr>
<tr>
<td>28/11/13</td>
<td>1:26:46</td>
<td>Audio data, Ruby, Brian and Jackie looking through photos and some general conversation Transcribed</td>
</tr>
<tr>
<td>13/12/13</td>
<td>1:16:36</td>
<td>Audio data, Ruby, Brian and Jackie looking through photos and some general conversation. Transcribed</td>
</tr>
<tr>
<td>28/01/14</td>
<td>0:56:55</td>
<td>Video data, Ruby, Brian and Jackie looking through life story book Transcribed</td>
</tr>
<tr>
<td>13/02/14</td>
<td>1:16:43</td>
<td>Audio data, Ruby, Brian and Jackie looking through life story book Transcribed</td>
</tr>
<tr>
<td>27/02/14</td>
<td>0:44:24</td>
<td>Audio data, Ruby, Brian and Jackie looking through life story book Transcribed</td>
</tr>
</tbody>
</table>

Total 7:12:53 All transcribed
**Information Sheet One - Using Life Story Books**

**What is a life story book?**

A life story book is a book compiled to capture memories and stories about a person’s life. It can be referred to over and over again by the person and their family and friends. Making a life story book can be an enjoyable and empowering activity. Many people will claim they haven’t done ‘anything special’, however all memories and stories should be cherished and the book is a way to celebrate the person and their life. Life story books capture all sorts of memories and issues that are important to a person’s identity and capture the little things that make them unique.

At times of ill health life story work can help focus back on to the person and what is important to them and this can be used to think about life now and in the future. Life story work is never finished. Books can always be added to with new pictures or new stories.

**How should we use our book now?**

This is up to you, however, people often find looking through their book from time to time, either on their own or with others, sparks off memories and conversation. In this way the book draws upon important long-term memory, emphasising what people can remember. Reminiscing in this way can raise self-esteem and improve well-being. Because labels are provided for names and information, this can help when searching for a word or a name.

You can add new events and information to your book. So, for example, if you go away on holiday or to a wedding, put a photograph in the book to mark the event. Other memorabilia such as leaflets or tickets can also go in. Do not worry if you can’t scan and type into the book. You can stick a photo to the page using a piece of sellotape behind the picture and write underneath. Books are to be used, rather than to stay as an untouched resource on a shelf. Over time the book may become a bit bashed about, but that’s fine it shows it is being used.

**What if some of the pictures provoke less interest?**

We make life story books so that you can take out any photographs that do not spark off conversation and memories, and add in any new one’s that do. Over time your interests may change and the book may need to reflect this. Therefore, if you notice certain pictures do not seem to be interesting or helpful, please feel free to take them out. You can save them elsewhere as a record of important events; it just might be at the moment this is not something that particularly sparks off memories or conversation for you.

**What if some of the pictures are upsetting?**

When making life story books we try and make sure any material in the book does not upset you. Sometimes events are sad but you may want them in your book as it is an important part of your life. Other times, even happy memories can spark off other memories that might be sad. If, over time, you find that certain pictures make you
upset, again, please feel free to take them out. This book is your book and you can change it as you wish.
Information Sheet Two - Common Questions

What is semantic dementia?
Dementia is an umbrella term used to describe a range of conditions that can affect a variety of brain functions. These days most people have heard of Alzheimer’s disease and are aware of some of the features of this condition. However, there is less public awareness about other rarer types of dementia, including a spectrum of conditions that often goes under the heading ‘frontotemporal dementia’. One type of frontotemporal dementia is ‘semantic dementia’.

In semantic dementia there are changes within the temporal lobes of the brain. The temporal lobes store an individual’s general and personal knowledge about the world that has been accumulated and learnt over the life span. This includes storage of the meaning of words, objects and concepts. This storage is called ‘semantic memory’ (i.e. meaning). This type of memory is particularly important when talking, for example, in finding the right words or being able to associate a place name with the exact place, or a person’s name with the particular person etc. It is thought that in semantic dementia the organisation and storage of this conceptual knowledge is affected. This makes it harder for the brain to sort through information quickly, both when trying to think of words when talking, and trying to find the meaning of words when listening.

How is semantic dementia diagnosed?
There is not one test that can diagnose semantic dementia. Diagnosis is carried out by piecing together information from memory and language tests, the history of the problem(s), physical examination and brain scan results. This process involves examining the pattern of symptoms. This is because semantic dementia does not affect all areas of the brain. Instead, it affects an area within the temporal lobes that is involved in processing language, meaning and memories associated with this.

How does semantic dementia affect people?
People with semantic dementia often say they have difficulty with making connections between words they hear and the meaning, or association, of that word. Most commonly this occurs with the names of less common people and places. Sometimes people find they have difficulty finding the names of less common people, places or objects when they are talking. Memory is more subtly affected in semantic dementia, in that memory that involves words may be affected more than memory for events, e.g. forgetting something you have been told, but memory for what has happened recently is less affected.

Why have we never heard of semantic dementia before?
It has been known for many years that there is a collection of conditions that appear to present with issues with language and words, rather than starting with the more typical pattern of forgetfulness. In older books these conditions were all labelled under the heading of Pick’s disease, named after the Czech Neurologist, who described such conditions back in the 1890’s. Since the 1980’s and 1990’s there has been further research studying these conditions and, at this time, semantic dementia was identified as a clinical syndrome. The condition has a different profile of both difficulties and retained skills than seen in other dementias such as Alzheimer’s disease.
Semantic dementia is classified as a type of frontotemporal dementia. There are three main types of frontotemporal dementia: ‘semantic dementia’, ‘primary progressive aphasia’ and ‘behavioural variant frontotemporal dementia’. The first two conditions present more with difficulties with language and word finding, whereas the last condition presents with changes in personality and behaviour. When looking up the condition the different labels often make it hard to find accurate information. Sometimes leaflets and websites collapse all the different types of frontotemporal dementia together. However, this can be misleading, as although there is some overlap in the conditions, individuals may have very different symptoms. It is also important to be aware at all times, that not all individuals develop all of the symptoms that may be described under a given condition.

**If the person tried harder would he/she be able to remember or associate the words?**
No, the problem is not one of attention and concentration and so thinking harder does not make things any easier. Sometimes putting the person on the spot to think of an exact word can actually have the opposite effect, because they become more frustrated and this can interfere with their thinking. Having time to think and giving the person more information to help them associate the word with its meaning is generally the best option. It is best to think of something that is personally related, e.g. if it is a place they are trying to remember, say something about when you last went or what you did there.

**What can we do to keep stimulated?**
Across the dementias there is evidence that keeping physically, mentally and socially active as much as possible helps people live better with their condition. This includes regular exercise, socialising with family and friends, attending activities in the community and engaging in hobbies. Concentrating on what you can do, rather than what you can’t, is an important part of this. Many people with semantic dementia, for example, find love of music and singing important and this helps their general well-being. Music bypasses the language system and concentrates on retained abilities and so activities like listening to music, singing groups or even dancing at the pub all help focus on activities that a person can do.

**What if we need more information or support?**
Your local memory service will be able to give you advice on other local services if you feel you, or your family, need more support. The Alzheimer’s Society, despite the name, provides support for people with all kinds of dementias and has both local and national offices and a website for information. The Frontotemporal Dementia Support Group is based in London and also has a website with further information should you need it with time.
Information Sheet Three – Conversation and Semantic Dementia

Dementia – Information for families

Areas involved in conversation:

- Memory
  - To remember the event/topic under discussion
  - To remember if you’ve told this story before
- Understanding
  - To understand and associate the words and details used by others, e.g. names, places etc.
- Expressive skills
  - To find words and express ideas.

Conversation brings all these abilities together in a fast moving manner.
In everyday conversation things can go wrong for a variety of reasons, this is the same for us all, whether we have dementia or not. Much of the time people with early semantic dementia may be fine in conversation and enjoy talking, with little difficulty. However, there may be instances when they need a little extra help or structure. Many of the strategies that are of use in semantic dementia, therefore, are those that we would all use in everyday conversation.

Things can go wrong in everyday conversation if:

1. The person cannot remember the event, topic or person under discussion. They may need help to:
   a. Clarify the event or person in their mind, e.g. who do you mean? Where was this? Giving extra information therefore helps this process of clarification. This tends to be more successful if the information is personally relevant, e.g. by describing when the person last went to a specific place and what they did there.

2. The person cannot find the words to express what they want to say. This is most likely to happen with less common or unusual words, or the name of a person or place they see less often. They may feel like it’s on the tip of their tongue. They may need help by:
   a. Being given time to think
   b. The other person suggesting a likely word, “do you mean x”
   c. Being asked to “show me”.
   d. Being given time to go away and think about it and come back to it later, e.g. “Don’t think about it now…we just can’t get it…it will come back to you later”. This is to acknowledge the problem but to diffuse any rising frustration.

3. Sometimes a person may use a word like ‘thingy’ or ‘what’s-her-name’ instead of the actual word or use an unusual way when expressing something. If it is obvious from the context what they mean, just respond as though the person has said the words correctly. Try not to correct them as this highlights their errors and may dent their confidence or irritate them. There is no
evidence that correcting helps a person get it right next time. It is possible, however, to indirectly give the right word in a natural way:

Speaker A - “when I went to the shop I saw what’s-her-name with the dog”  
Speaker B - “oh….Wendy…she’s got that little terrier hasn’t she…”

4. The person may not fully understand what the other person is saying, for example, if the topic is unfamiliar or the person is talking too fast or giving too much information at once. For example, explaining how a new computer system works would cause most of us problems because it is a complex area. The person may need help by:
   a. Slowing the conversation down and showing them what you mean.
   b. Being given time to think.

5. Sometimes a person may forget they have told a story already to a given person. We all do this from time to time and we may say “have I told you this…I can’t remember”. Sometimes people with semantic dementia may lose the awareness of this and so repeat the same story. What you do about this depends often on the context. In many instances the person is enjoying telling the tale and, so, letting it go is the best approach. You also have to remember that you, as a carer, might be more aware than others.

In certain instances, however, perhaps where others are less aware of the person’s difficulties or you are concerned others may be less understanding this may be more delicate. Rather than say “you’ve already told them that…” which only draws attention to this issue, you could try saying something that highlights why this story might be worth hearing again, e.g. “oh this is funny this one…”, or “she/he really feels strongly about this at the moment” etc. This area also relates to whether you have shared the diagnosis with others. Who you tell is entirely up to you both. If you choose to tell others, because semantic dementia is a rare dementia and many people have not heard of it, you might want to explain that the person has some memory problems and that others just need to bear with them with this issue.

6. Sometimes too many people are talking at once and it is hard to follow the conversation, or the situation is very noisy and they cannot concentrate.
   a. It might be best to avoid important conversations at such times, or ask people to repeat, or speak one at a time.
   b. Turning off the TV/radio etc. or going out of the noisy environment to talk.

7. It is important to be aware that humour can involve complex language and problem solving skills. Sarcasm involves not only understanding what someone said, but also why they literally (this time, in this context), did not mean exactly what they said. Occasionally people with semantic dementia may misread the humour or teasing of others, or the tone of their voice, because of their memory and language difficulties.
Conversation and emotions

Sometimes family members feel under pressure to keep the person “stimulated and thinking.” There is, however, a fine line between stimulation and frustration and so when frustration rises it is important to think about whether to pursue this way of doing things or this activity. A good example of this can be in managing word finding problems. Whilst it is important to give the person time to think, if they are becoming frustrated, it might also be important to give them the word, if you know it, to reduce this frustration. It might also be important to think about accidentally highlighting a person’s difficulties within conversation. Sometimes the little things matter, an example of this might be these three little words: “don’t you remember….,” e.g.

- So what are we going to do today?
- Don’t you remember we said we were going out for a meal
- Did we (showing irritation their memory problem has been highlighted)

In this above example the problems with memory have accidentally been highlighted. Finding ways to indirectly prompt without highlighting someone has forgotten or is not able to do something well, is a worthwhile skill to learn and manages emotions as well as conversation. So reworking this example it could be:

- So what are we going to do today?
- Well we were talking about going out for a meal weren’t we
- Oh right…that will be nice…

It is not possible, as a family member looking after someone with dementia, to get it right all of the time and there will be times when you both get frustrated. However, adopting a problem solving approach is useful when things do cause frustration or go wrong. So thinking about:

- What happened?
- What was going on?
- What was the person’s reaction and why?
- What might I do differently next time?

This sometimes helps you find your way through to trying a different approach next time. Talking to your memory clinic team is also important if you need further advice or support.
Ruby and Brian – Further Examples of Conversation Analysis Data

Extract 48) - Holding the conversational floor (15/12/13)

This long example illustrates the manner in which Ruby moves, step by step, away from the initial topic. Prior to this sequence I had asked Ruby if she had worked. She tells me about having a part time job, that she had to give up, because it was too much with a young family. Ruby then goes on to say about missing friends and this seems to spark off in her mind her younger days prior to marriage when she went out. As is usual, as a listener of a story I respond with minimal feedback responses “mm” and “yeah”. However, my questions at the end 061 and 065 (in green), about whether this was before she was married, indicate I’m not clear when the story took place. Interestingly, I do not mention ‘work’ but Ruby herself returns to this topic in 070 indicating she has remembered that ‘work’ is what we were talking about at the very start of the conversation, quite some time before. Also of note is Ruby’s numerous uses of “and”, “and then” and “but” linking elements of the story (in bold).

Talking about her part time job when the kids were small

001 R so I just stopped it then
002 J yeah
003 R and like I say you miss friends and everybody
004 and you know with not going out
005 J yeah
006 R but I used to go out at er(.) I don’t know who
007 used to it was now it was friends er from
008 Stretford I go out with them and er well I mean
009 I was with my mum then
010 J mm
011 R but we went to Palais and everything
012 J oh right
013 R an we used to and I used to get on the 42 bus
014 back but I had to get off at Chorlton and then
015 wait for (.) what were number then it weren’t
016 number eight then were it oh that were Stretford
017 going around Stretford and er (0.0) I used to
018 wait and sometimes I’d get off the bus at number
019 eight and just go in
020 J mm
021 R and I couldn’t get across and they were all
022 getting off you know just taking their time
getting off and everything and then I had to wait for getting over the road and then I had to walk to get to the bus stop yeah and then it were just going off sometimes so as I say I had to walk it to Stretford from Chorlton [So you’d missed the bus home] But it were smashing that because everybody said hello and hhh nothing like it is today frightened to death [you know hey] frightened yeah and it was smashing you know and I’d say hello and then sometimes I’d see them you know regular ones and yeah hello enjoy your night I said yes you oh yeah I’ve had enough to drink to that effect you know yeah and it was smashing but it was so lonely like going under bridge because it were all like a field and then you went over [bridge and] [See you] couldn’t do that today [no ] could you you wouldn’t do that today would you oh no no and then you’d come to the houses mm and then you’d walk straight up and then go to main road and then I had to walk all the way down then to where the police station was and our (. ) pub was then I had to (. ) go up left then go up right and then just turn in and our house was there you know mm and there was a train station and all there and everything you know so was that before you met before you were married [yes that was] before she met me yeah yeah before you married yeah] [yeah] but like I say everything went but like I said then I got married and I didn’t work then did I
The main issue here is that the extensive detail does not appear necessary to the topic at hand and leaves me struggling to follow the sense of the conversation and filter through what is relevant, and what is not, at this point in the conversation.

**Extract 51) - Life story book moving forward the conversation (I 31/03/14)**

We have been looking at the life story book and one topic has led to another and Ruby is telling a long story about a recent argument in the pub, which has become rather circular. The presence of the life story book allows me to move Ruby off this topic without causing offence (line 002-003 in green):

[very long conversation about an argument in the pub]

001  R  I know yeah so-
002  J  We’ve put in about your ballet and tap haven’t we ((showing book))
003  R  Yes hhhhhhh

[Ruby moves on to tell me story about having to give up “ballet, tap and toe”]
APPENDIX 14

Case Study 5 Ken and Brenda - Additional Information

Information Sheet One - Semantic Dementia: Common Questions

How is semantic dementia diagnosed?
The is not one test that can diagnose semantic dementia. Diagnosis is carried out by piecing together information from memory and language tests, the history of the problem(s), physical examinations and brain scan results. This process involves examining the pattern of symptoms. This is because early semantic dementia does not affect all areas of the brain. Instead, it affects a small area within the temporal lobes that is involved in processing language and meaning.

How does semantic dementia affect people?
People with semantic dementia often say they have difficulty with making connections between words they hear and the meaning or association of that word. Most commonly this occurs with the names of less common people and places. Sometimes people find they have difficulty finding the names of less common people and places when they are talking. Memory is more subtly affected in semantic dementia in that memory that involves words may be affected, e.g. forgetting something you have been told, but memory for what has happened recently is good.

Why have we never heard of semantic dementia before?
It has been known for many years that there is a collection of dementia conditions that appear to present with issues with language and words, rather than starting with the more ‘typical’ pattern of forgetfulness. In older books these conditions were all labelled under the heading of Pick’s disease, named after the Czech Neurologist, who described such conditions back in the 1890’s.

Since the 1980’s and 1990’s there has been further research studying these conditions and, at this time, ‘semantic dementia’ was identified as a clinical syndrome. The condition has a different profile of both difficulties and retained skills than seen in other dementias such as Alzheimer’s disease.

When looking up the condition the different labels often make it hard to find accurate information. Sometimes leaflets and websites collapse all the different types of dementia together. However, this can be misleading, as although there is some overlap in the conditions, individuals may have very different symptoms. It is also important to be aware at all times, that not all individuals develop all of the symptoms that may be described under a given condition.
If the person tried harder would he/she be able to remember or associate the words?
No, the problem is not one of attention and concentration and so thinking harder does not make things any easier. Sometimes putting the person on the spot to think of an exact word can actually have the opposite effect because they become more frustrated and this can interfere with their thinking. Having time to think and giving the person more information to help them associate the word with its meaning is generally the best option. It is best to think of something that is personally related, e.g. if it is a place say something about when you last went or what you did there.

What can we do to keep stimulated?
Across the dementias there is evidence that keeping physically, mentally and socially active as much as possible helps individuals live better with their condition. This includes regular exercise, socialising with family and friends, attending activities in the community and engaging in hobbies.

Reading, writing and working on the computer are also important activities that can stimulate language. One of the best ways to keep stimulated is to think about writing an autobiography. This might seem like a daunting task but can be broken down into more manageable chunks and does not have to be done in a chronological order. Sometimes this is done using text, for others this might involve collecting photographs or even film or music.

One of the best ways to start this is to think about writing about a more manageable topic in your life. Try a topic you are passionate about or that has happy memories:

- My favourite hobby.
- Places I have loved.
- My memories of growing up.
- My first job or my years at college.

In this way the memory, vocabulary and meanings associated with the person’s own life are stimulated. Reading through this material can also then stimulate these memories.

Concentrating on positive events, memories and photographs has also been shown to be important for improving mood.
Information Sheet Two: Summary Sheet - Areas Discussed

We have discussed that semantic dementia is largely about connections, so linking a word, name or idea with the concept or memory of that word or name. The condition affects a region within the temporal lobes.

1. **Keeping Well** – There is evidence across all of the dementias that taking care of one’s physical and mental health are important:
   a. Exercise for example has been shown to have significant benefits.
   b. Taking care of one’s mental health is also important to keep well.

2. **Keeping Active Socially** – This includes keeping up with existing social contacts and activities and, if necessary, trying out new ones. Social contact provides multisensory stimulation that uses language and memory skills.

3. **Identifying Strategies to Help:**
   a. **Enriching talk** – When problems with understanding or linking a place name or person’s name to the place/person further information may be needed. This often includes personally relevant details, such as when, or where, you last saw them, or a salient detail that makes them memorable to you (e.g. Peter, that always wears that awful hat) or if it’s a place, when you might have been there, what you did there, or other details that may link it with the importance to you.
   b. **Enriching messages** – People often come back to written messages and find that they may not be able to connect them with the idea, or person, they were writing about. It is, therefore, important to just add in extra details to help this, e.g. instead of writing a name and phone number down, add in name, number and a sentence “John the plumber about the boiler.”
   c. **Place names when out and about** – If place names feel hard to link to the actual place, use the maps option on the phone.

4. **Keeping Names Going** – We have discussed that ‘testing’ oneself in the production of names, e.g. artist’s names, is probably best not done in isolation, i.e. going down a list or round the house. A better way to do this is to practice the name in the context of personally relevant detail about that name. So therefore, writing a paragraph about each painting or print and reading through these on a regular basis. The name then is stimulated within a personally relevant context to hang it on, and again we come back to issues of enrichment.
# APPENDIX 15

## Charting Across Case Studies

Table A15.1 - Charting issues across case studies

<table>
<thead>
<tr>
<th>Area Examined</th>
<th>CASE ONE Peter and Joanna</th>
<th>CASE TWO Sarah and Reg</th>
<th>CASE THREE Doug and Karina</th>
<th>CASE FOUR Ruby and Brian</th>
<th>CASE FIVE Ken and Brenda</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Linguistic issues in conversation</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Word finding</td>
<td>Severe struggle evident on video, observation and noted in field notes.</td>
<td>No struggle. Fluent when talking about certain topics. Evidence of empty terms.</td>
<td>Fluent but significantly empty of content with English and non-English ‘jargon.’</td>
<td>No struggle. Fluent but with a lack of precise terms ‘whatsit’ ‘dong dong’ etc.</td>
<td>Described by Ken but not evident in his talking at observation or on video data.</td>
</tr>
<tr>
<td>Comprehension</td>
<td>Significant problem - failure to physically respond or lack of expected verbal response. No repeating words back. Supported by visual materials, e.g. IPAD, showing.</td>
<td>Not a significant problem to them. Reg reports keeping things simple. Adds in extra details to trigger. Some repeating back words back evident on video.</td>
<td>Appearing to understand, e.g. nodding, ‘yeah’, ‘absolutely’. Video data shows very significant problems with understanding in ADLs. Showing helps.</td>
<td>Subtle problems occasionally evident. Misunderstanding Brian’s intent, e.g. he is joking but easily offended.</td>
<td>No evidence on video data but described problems of linking names and place names to the person and location.</td>
</tr>
<tr>
<td><strong>Conversation Issues</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lack of conversation</td>
<td>Significant problem reported &amp; evident in conversation</td>
<td>Significant problem reported &amp; evident in conversation</td>
<td>Significant problem reported &amp; evident in conversation</td>
<td>Brian reports Ruby starting less conversation</td>
<td>Ken reports himself ‘taking a back seat’ more now.</td>
</tr>
<tr>
<td>Area Examined</td>
<td>CASE ONE Peter and Joanna</td>
<td>CASE TWO Sarah and Reg</td>
<td>CASE THREE Doug and Karina</td>
<td>CASE FOUR Ruby and Brian</td>
<td>CASE FIVE Ken and Brenda</td>
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</tr>
<tr>
<td></td>
<td>data when alone at home.</td>
<td>data when alone at home.</td>
<td>data when alone at home.</td>
<td>On occasion reported by Brian.</td>
<td>No.</td>
</tr>
<tr>
<td>Repetitive questions about the routine</td>
<td>Yes - What are we doing today? Conversation opener.</td>
<td>Yes - what time the carer was coming, asking for particular foods, tablets etc.</td>
<td>Not in present data but present in previous data set.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced repertoire of topics of conversation</td>
<td>Yes, recurring topics, often not initiating new topics. Evident in interviews, observations and conversation data.</td>
<td>Yes, recurring topics, not initiating new topics. Evident in interviews, observations and conversation data</td>
<td>In the past but talk hard to follow now. Lack of language skills now to initiate topics. The Navy, however, appeared to be a topic that led to greater recognition.</td>
<td>Yes, evident when out socially, telling same stories. Evident in interviews, observations and conversation data. Introducing new topics less now.</td>
<td>Not reported or observed.</td>
</tr>
<tr>
<td>Holding the conversation floor</td>
<td>Not an issue</td>
<td>Not an issue now but present in past data in interviews</td>
<td>Yes - evident in conversation data and interviews.</td>
<td></td>
<td>Not an issue</td>
</tr>
<tr>
<td>Other recurring conversational behaviours and skills</td>
<td>Showing diary repeatedly to visitors. Writing when goes for run repetitively.</td>
<td>Singing in conversation Direct reported speech in stories. Banter.</td>
<td>Enactment evident with direct reported speech. Singing in conversation ‘Posh’ voice.</td>
<td>Complaint stories. Direct reported speech within long stories. Banter.</td>
<td>Issues reported by Ken not evident in the conversation samples.</td>
</tr>
<tr>
<td>Most significant issue with conversation</td>
<td>How manage word finding</td>
<td>Lack of varied conversation lack of</td>
<td>Ensuring care home staff meet Doug’s</td>
<td>Conversational issues when out exposing</td>
<td>Ken’s severe anxiety about his</td>
</tr>
</tbody>
</table>

437
<table>
<thead>
<tr>
<th>Area Examined</th>
<th>CASE ONE Peter and Joanna</th>
<th>CASE TWO Sarah and Reg</th>
<th>CASE THREE Doug and Karina</th>
<th>CASE FOUR Ruby and Brian</th>
<th>CASE FIVE Ken and Brenda</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>problems, including test questions and prompts for accuracy.</td>
<td>initiation from Sarah.</td>
<td>interactional needs.</td>
<td>Ruby as ‘different’.</td>
<td>symptoms, although appear very mild.</td>
</tr>
</tbody>
</table>

**Adaptation, emotional and carer issues**

**Adaptation**
- Pedagogic behaviour in conversation a challenge for them both. Joanna trying to keep life as it was prior to dementia. Peter aware of diagnosis but reconciled things could be worse.
- Reg adapted well. You have to play the hand you are dealt (Reg). You gotta get on with it (Sarah). Tag questions to give information and facilitate participation. Test qns to draw in.
- Karina adapted well, transition to nursing care initially difficult. Test questions & tag questions used to draw Doug into interaction and facilitate participation.
- Relatively recently diagnosed, still coming to terms with condition.
- Recent diagnosis, Ken very worried about his symptoms. Testing behaviour making him feel worse – not helping.

**Working together, apart, conflict**
- Conflict, working apart. Joanna – nothing could be worse than dementia. Peter – things could be worse. Past close bond.
- Working together, similar views.
- Working together it would appear, with a history of previous relationship challenges.
- Working apart in some ways. Not discussing the condition, different views on seeking help, information and advice. Brian working in isolation.
- Conflict, working apart – different views of the dementia, severity, progression and how to manage symptoms.

**Emotional issues in**
- Emotion in conversation Not a concern. Not a concern. Stress for Brian in Brenda spouse not
<table>
<thead>
<tr>
<th>Area Examined</th>
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<th>CASE FIVE Ken and Brenda</th>
</tr>
</thead>
<tbody>
<tr>
<td>conversation</td>
<td>a concern. Carer grief and loss, mourning for past life.</td>
<td>particular in trying to hide dementia to others.</td>
<td>worried. Ken very worried and anxious.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other potential barriers to adaptation</td>
<td>Carer burn out. Isolation from local provision.</td>
<td>Expertise lost in the transition from home to nursing home.</td>
<td>Lack of information about condition.</td>
<td>Lack of adequate information about early stage semantic dementia.</td>
<td></td>
</tr>
<tr>
<td>Targets for therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conversation behaviours and interaction-focussed therapy</td>
<td>Required and targeted in therapy via interaction-focussed therapy</td>
<td>Not required</td>
<td>Not required</td>
<td>Unwilling to video themselves alone. Advice given.</td>
<td>Unwilling to video themselves alone. Advice given</td>
</tr>
<tr>
<td>Area Examined</td>
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</tr>
<tr>
<td>Life story issues</td>
<td>Good with photographs – remembering more with photograph there. Required written word directly on photos next to faces.</td>
<td>Lack of recognition of people and places in photos, Book and memory box ‘flat’ conversation . Music a success. Performance aspects to data – playing to audience, playful and creative.</td>
<td>Severe lack of recognition of people and places in photos. Performance and nonverbal interaction – ‘posh voice’, clearly playing to the audience.</td>
<td>Lack of recognition of places, but photo aiding talk about people, appearance and general issues.</td>
<td>Able to engage in this himself, but needed structure and encouragem ent. Led to other activities, but again therapist support to identify actions and goal setting.</td>
</tr>
</tbody>
</table>
APPENDIX 16

Dissemination Activities

Peer Reviewed Articles – Published


Peer Reviewed Articles – in Press


International Conference Presentations


Kindell, J., Sage, K., Keady, J. & Wilkinson, R. ‘What does the biopsychosocial model have to offer in the management of communication in semantic dementia:
evidence from a family case study?’ Poster presentation to the 8th International Conference on Frontotemporal Dementia, Manchester, 5-7th September 2012.


**National Conference Presentations**


**Kindell, J.** ‘From practice to PhD’ to the Royal College of Speech & Language Therapists Annual Conference, Manchester, 11th September 2012.


**University Presentations**


**Kindell, J.** ‘Interaction and practice in frontotemporal dementia’ to University of Sheffield, MA in Dementia, 25th February and 13th May 2015.

**Kindell, J.** ‘Innovative practice in life story work’ to Practice Development for Primary Care Nurses, Manchester Metropolitan University, 26th March 2015.

**Kindell, J.** ‘From MClinRes to PhD’ to MClinRes, University of Manchester, 16th March 2015.

**Kindell, J.** ‘The Dementia and Ageing Research Team’ to the University of Manchester Alumni Association, 2nd October 2014.

**Kindell, J.** and Keady, J. ‘Creativity in semantic dementia: Supporting couples/families to sustain conversation at home’ to School of Nursing, Social Work and Midwifery, University of Manchester internal seminar series, 22nd July 2014
**Kindell, J.** ‘Supporting conversation in semantic dementia’ to the School of Nursing, Social Work and Midwifery Mental Health Research Group, University of Manchester, 23rd November 2012.

**Kindell, J.** ‘Exploring conversation in semantic dementia’ to the Neuroscience and Aphasia Research Group, University of Manchester, 21st June 2012.

**Kindell, J.** ‘Exploring conversation in semantic dementia’ to University of Manchester Alzheimer’s Research Trust PhD study afternoon, 20th June 2012.

**Practice Orientated Presentations**

**Kindell, J.** ‘Music and frontotemporal dementia’ to Stockport Frontotemporal Dementia Carers Support Group, 17th July 2015.


**Kindell, J.** ‘Innovative practice in life story work’ to Stockport Older People’s Mental Health Service, 10th June 2015.

**Kindell, J.** ‘Music and life story work’ to Signpost Stockport Carers Group, 19th March 2015.

**Kindell, J.** ‘Life story work in semantic dementia’ to Pennine Care NHS Trust Board, 26th November 2014.

**Kindell, J.** ‘Thank you for the music – innovative practice in life story work’ to North West Speech and Language Therapy Clinical Excellence Network in Old Age Psychiatry 9th October 2014.

**Kindell, J.** ‘Carer experience in semantic dementia’ to Stockport Frontotemporal Dementia Carers Support Group, 19th September 2014.


**Kindell, J.** ‘Practical clinical aspects in primary progressive aphasia and semantic dementia’ to the Younger Onset & Memory Service Team, Worcester, 14th November 2013.

**Kindell, J.** ‘Living with semantic dementia’ to the Admiral Nurses North West Education Meeting, 12th September 2013.

**Kindell, J.** ‘Supporting conversation in semantic dementia’ to Greater Manchester West NHS Trust, Research in Dementia study day, 18th July 2013.
Kindell, J. ‘Providing support for communication in semantic dementia’ to Northern Speech and Language Therapy Special Interest Group in Old Age Psychiatry, 30th April 2013.

Kindell, J. ‘Working with frontotemporal dementia’ to the Speech & Language Therapy Special Interest Group (Adult Acquired), Dublin, 7th December 2012.