

**Coping with young onset dementia:
Perspectives of couples and
professionals**

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ABSTRACT

There has been little research examining experiences and coping processes associated with young onset dementia. Adjustment to such conditions involves couple relationships, family and wider social context, and is affected by available services and professionals involved. The aim of this qualitative study was to explore responses of couples and professionals to the unique challenges presented by young onset dementia.

Participants were recruited by a South Wales memory clinic. Six couples and six professionals each engaged in a semi-structured interview, where they were invited to discuss their experiences, coping strategies and factors that impacted on their psychological adjustment. Interviews were recorded, transcribed and analysed using Interpretative Phenomenological Analysis.

All of the couples in the study were in stable long term relationships. Five of the sufferers had Alzheimer's disease and one had frontotemporal dementia. Professionals had a variety of roles within young onset services and had worked in dementia services between 4 months and 30 years. Findings included: couple participants employed a range of coping strategies, experienced substantial role changes within the relationship and sometimes struggled to maintain hope. Couples reported finding significant benefits from meeting regularly with other couples facing the same challenge, as part of their negotiation of identity. Professionals spoke of added challenges of working with people with young onset dementia, partly as a result of an increased tendency towards identification with sufferers.

The study identified needs for clarity of information provision, flexible support and promotion of increased public awareness of young onset dementia. Findings highlight the importance of assessment of coping styles and support for positive adjustment throughout the diagnostic and treatment process, and the contribution and partnership of service users to service planning. Further research suggestions included identifying precursors of poor coping, recognition of positive consequences of dementia, and exploring perceptions and experiences of different professional groups.

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CHAPTER ONE: INTRODUCTION

1.1 Overview

This thesis will report on the process and findings of a qualitative exploration of the experiences of couples where one has been diagnosed with young onset dementia. It will also explore the views of professionals who work directly with younger people with dementia. A particular focus will be on the process of adjustment and coping by couples after they have received a diagnosis.

In Chapter One, the background and aims of the study and a review of the existing literature will be provided. This will encompass the epidemiology of young onset dementia, issues particular to younger people, and theories of coping and adjustment in this context. The impact on care and support will also be discussed, as will policies relevant to younger people with a dementia. In Chapter 2, the methodology for the current study will be presented, and the results will be presented in Chapter 3. Findings and implications will be discussed in Chapter 4, and this will also include considerations of limitations in this study and directions for further research.

1.2 Background to the study

The project was prompted by a service initiative by the Minister for Health & Social Services (Welsh Assembly Government, 2010). This constituted a report which emphasised that specialist services for younger people with a dementia should be devised and run in all areas in Wales. The Welsh Assembly Government accordingly awarded older people's services in each area in Wales a fund to set up new Young Onset Dementia Community Services specifically for younger people with dementia.

Following this, there has been a recent change in guidelines for dementia care (National Institute of Health and Clinical Excellence, 2011) to extend the potential prescription of anti-dementia medication to those with mild to moderate dementia, with resulting implications for clinical practice in terms of the timing of diagnosis. The launch in Wales of "Intelligent Targets" (Welsh Assembly Government, 2011) also aimed to improve existing services including reducing the time between onset of symptoms and diagnosis, quality of care in hospital in both general and dementia

units, improving the prescribing practices for people with dementia, and improving and supporting quality of life for the carers of people with dementia.

1.3 Terminology

A dementia in someone under 65 years of age is typically referred to as “young onset dementia”, but is also sometimes referred to as ‘working age dementia’. “Early onset dementia” is sometimes used to refer to younger people, but also to refer to the early stages of dementia irrespective of age (Cox & Keady, 1999). Throughout this study, the terms ‘young onset dementia’ and ‘younger people with dementia’ will be used to refer to people under 65, and “older people” will be used to refer to those over 65. This reflects the current structure of service provision.

1.4 Literature Review Process

A comprehensive literature review was performed to explore areas of interest relevant to the topic of the current study, and to review the large body of research related to young onset dementia. The review was carried out prior to and during the process of data collection and analysis, from November 2011 through to February 2012.

The review was carried out by exploring literature sources such as psychological, nursing and medical journals and databases, media and government resources. Databases searched were: Cardiff University Full Text Journals; AMED (Allied and Complementary Medicine); EMBASE; HMIC (Health Management Information Consortium); ICONDA; Ovid MEDLINE; PsycINFO; PsycArticles Full Text. Potential papers, reports and book chapters were identified from reference and citation lists where they appeared to be relevant. Google and Google Scholar searches were made using the same search terms, and a search was conducted of the Alzheimer’s Society database. Recommendations from people working with young onset dementia were also taken into account.

The review involved a number of stages. The initial strategy applied was to use general search terms (e.g. ‘dementia’ AND ‘coping’, plus possible variations of these words) and then to refine the searches using more specific terms. However, this strategy revealed a very large body of literature. Where search terms or

combinations had a high volume of results, searches were refined by removing duplicates, and selecting only those studies published in English, and those using human participants and adult populations. A further filtering strategy was to include only articles published in or after 1996 until the current date; it was felt that this would fit with the study emphasis on current treatment and services for dementia, as well as serving to simply narrow down the search. However, references prior to this were considered if they included ideas which were highly relevant. In addition, many of the results obtained were not related to research into dementia, and thus results were only reviewed further if they seemed to be directly relevant to dementia. Articles were also selected on the basis of whether the full text was available.

The general search terms used were: “Dementia”, “Young* dementia”, “Early* dementia”, “Working age dementia”. Then more specific ideas were searched for within these articles e.g. “Coping” “Adjustment”, “Couples”. Search terms relating to current services were: “Memory Team / Clinic”, “Diagnosis”. The researcher used word truncation and Boolean operators to refine searches and to search for possible variations of search terms. The search terms were selected to reflect the objectives of the study and to be as inclusive as possible.

Once these searches were carried out, each abstract was read and selected as relevant if it met one of the criteria specified below:

- Reviewed or reported research into young onset dementia;
- Reviewed or reported research into coping with dementia;
- Considered the perspective of couples where one has dementia;
- Considered service user/carer or staff perspectives on diagnosis, treatment, support and services, coping and adjustment;
- Reviewed or reported research relating to the diagnosis, treatment and support of those with young onset dementia;
- Reviewed or reported research into current services related to young onset dementia;
- Used similar research methodology to the current study.

The researcher thus viewed all abstracts identified as relevant, and then endeavoured to access the full text of articles that seemed to be particularly relevant to the current study. A table detailing the searches carried out and the number of articles resulting from each can be found in Appendix 1.

General search engines were also utilised, to search for news stories and public discussions on the topic. Other sources searched included websites of voluntary and support organisations (e.g. Alzheimer's Society), policy and service websites (e.g. National Institute for Health and Clinical Excellence (NICE); Welsh Assembly Government, Department of Health); and professional interest organisations (e.g. Social Care Institute for Excellence (SCIE), British Psychological Society, Psychology Specialists working with Older People (PSIGE)).

Information garnered from these sources is discussed throughout this chapter. Eight papers were considered to be particularly relevant to the current study, and these are reviewed in detail at Section 1.12.1.

1.5 Dementia

Dementia is a general term for a range of disorders resulting in physical changes occurring in the brain. Its classification is still unclear, and it has been considered to be a "disease", or a 'syndrome' (e.g. Baldwin & Murray, 2003; Davis, 2004; Peng, 2003). The term 'dementia' itself is frequently used as a broad description or umbrella term, rather than focusing on the conditions related to the particular type of dementia (Jorm *et al.* 1987).

Dementia can be thought of as an organic mental disorder, caused by changes to the brain and resulting in progressive deterioration (Kitwood, 1997). It may result in:

- Memory difficulties
- Attention and concentration difficulties
- Personality changes
- Behavioural changes
- Mood and emotional changes
- Disorientation in time, day and place
- Difficulties in recognition, understanding and comprehension
- Difficulties in language and communication

- Inappropriate interaction
- Difficulties in reasoning, planning, and learning new information
(Cox & Keady, 1999; Welsh Assembly Government & Alzheimer's Society, 2011).

The symptoms and rate of decline in cognitive and other areas of functioning vary between individuals, and some symptoms are more likely to occur with certain types of dementia (Alzheimer's Society, 2002).

Despite great advances in medical understanding, no cure currently exists. Some pharmacological treatments have been shown to slow progress for a period, but do not stop the progress of the disorder or reverse its effects. This makes the diagnosis a subject of many people's fears concerning their future (Clare, 2002; Corner & Bond, 2004). With the progression of dementia, every area of cognitive functioning may be affected, and eventually physical functioning will decline. The effects can make dementia sufferers extremely vulnerable (Welsh Assembly Government, 2011). Following a diagnosis of dementia, life expectancy will vary according to the type of dementia and complications resulting from it, and the stage at which the person is diagnosed. It is thought that a person may live with Alzheimer's disease for up to ten years, whereas someone with a vascular dementia may live for 1-2 years after its onset (Ott *et al.* 1998; Welsh Assembly Government & Alzheimer's Society, 2011).

Dementia can affect anyone, irrespective of gender, ethnicity or class. However, some people may be at greater risk of developing a dementia, including:

- People with learning disabilities, particularly those with Down's syndrome (Kerr, 2007)
- People with high cardiovascular risk factors, such as high cholesterol, hypertension, and diabetes (Whitmer *et al.* 2005).
- Stroke survivors (Vermeer *et al.* 2003)

Other factors in a person's lifestyle, such as low physical activity and poor nutrition, may also increase the risk of developing a dementia (Alzheimer's Society, 2002; Rovio *et al.* 2005; Xie *et al.* 2008).

Worldwide, there are currently estimated to be over 35 million people with dementia, with estimated projections of an increase to over 115 million people worldwide by 2050 (Alzheimer's Society, 2012). In the UK, the prevalence is around 750,000, with

a predicted increase to over 1 million by 2025; in England, current estimates are 648,898 people, in Northern Ireland, current estimates are 18,286 people, and in Wales, 43,614 are currently thought to have a form of dementia. Predicted increases in the prevalence of dementia are thought to be linked to an increase in life expectancy, due to advances in medical knowledge, treatment and healthcare. The cost of social care and informal care for dementia to the UK economy is currently thought to be higher than the costs of cancer and heart disease combined (Alzheimer's Society, 2012; Luengo-Fernandez et al, 2010).

The age of onset differs according to the type of dementia (American Psychiatric Association, 2000). Some estimated prevalence figures are shown in Table 1:

Table 1: Prevalence of dementia in the UK (Alzheimer's Society, 2012)

Age	Current estimated prevalence per head of UK population
40-64 years	1 in 1400
65-69 years	1 in 100
70-79 years:	1 in 25
80+ years	1 in 6
95+ years	1 in 3

There are approximately 800,000 people in the UK living with a dementia (Alzheimer's Society, 2012). Most estimated prevalence figures are based on referrals to services, and many more people may be undiagnosed. For those under 65 years of age, current estimated incidence in the UK is 16,000 (Alzheimer's Society, 2012). However, it is thought that the prevalence of dementia in people under 65 in the UK could be up to three times higher than this (Alzheimer's Society, 2012).

1.5.1 Aetiology of Dementia

Diagnostic criteria – namely the Diagnostic and Statistical Manual for Mental health Disorders (DSM-IV) (American Psychiatric Association, 2000), and the Classifications of Mental and Behavioural Disorder guidelines (ICD-10) (World Health Organisation, 1990) categorise types of dementia based on external patterns of symptoms, and in some cases, physical examinations and scans of the person's brain. Therefore, most

diagnoses are by definition tentative or hypothesised, though advances in cognitive testing and neuroimaging, as well as increased knowledge about the presentations of dementia, can often make the diagnostic process more reliable (Carpenter *et al.* 2008).

DSM-IV criteria divide dementias into categories according to aetiological diagnosis and behavioural symptoms (APA, 2000). The most common and well-known form is Alzheimer's Disease ("AD"), typified by gradual onset and deterioration of cognitive functions, usually beginning with memory and eventually resulting in total dependence with respect to almost all activities (Janicki *et al.* 2000). The first report of this presentation was by Alois Alzheimer in 1907, who examined the brain tissue of a 51 year old female patient who had deteriorated significantly prior to death (Moller & Graeber, 1998; Wilkins & Brody, 1969). This report described the 'senile plaques' and 'neurofibrillary tangles' that are now considered as neuropathological hallmarks of AD. These plaques coat the neurons and prevent the effective transmission of messages within the brain, resulting in a reduction in brain tissue (atrophy) and leading to loss of abilities (Probst *et al.* 1991). This atrophy will be more extensive than that seen in normal ageing (Hart & Semple, 1990). The plaques are the main focus for current biological research into the causes, prevention and treatment of AD (Alzheimer's Society, 2012).

Other forms of neurodegenerative dementia typically do not affect memory as markedly in the early stages, but rather progressively erode language, reasoning, visuospatial abilities, and aspects of character and personality (Weintraub & Morhardt, 2005).

Vascular dementia results from damage to the brain, typically multiple small blood clots (infarcts) resulting in loss of oxygen supply to areas of brain tissue and the death of those focal areas of brain tissue (Hart & Semple, 1990). The presentation will depend on the location and distribution of the infarcts and the size of the blood vessels involved. Progression is usually stepwise rather than gradual, following a pattern of sudden deteriorations when a new infarct is experienced, and with plateaus of stability in between. Control of underlying risk factors such as blood pressure may help to slow the progression of vascular dementia (Weintraub & Morhardt, 2005).

Many people will also suffer with 'mixed' dementia, which is usually of AD type alongside changes suggestive of vascular dementia, though other types of dementia can also present as 'mixed'.

Dementia with Lewy Bodies typically involves the experience of hallucinations and a fluctuating, vascular-type pattern of deterioration, often with some visuospatial difficulties. It is thought to be caused by protein deposits in the nerve cells of the brain, and typically affects the person's memory, concentration and language skills. This type of dementia has symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement. The progression of this condition can be confusing, as the person's abilities may fluctuate (Knapp & Prince, 2007).

Fronto-temporal dementia is a rarer form of dementia affecting the front of the brain and is more likely to affect people under the age of 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change. This classification also includes Pick's disease, which causes generalised brain atrophy, usually in the frontal or temporal lobes.

Parkinson's disease causes marked loss of cells from the neurons involved in dopamine production (Knapp & Prince, 2007), resulting in physical symptoms such as a tremor and/or rigidity. Neuroimaging cannot always detect Parkinson's disease differentially from AD (Jacoby *et al.* 2008).

Other, less common types of dementia include:

- Huntington's' Disease – A hereditary condition, involving substantial loss of neurons and proliferation of glial cells and resulting in progressive brain atrophy (Jacoby *et al.* 2008).
- Wernicke-Korsakoff syndrome, also known as Korsakoff's Syndrome – Symptoms and progression are similar to AD, but Korsakoff's is caused by prolonged and heavy alcohol intake, and may be linked to nutritional deficiencies. Research into the use of vitamin B12 has been promising, and linked to potential areas of research in AD (Meins *et al.* 2000).
- Binswanger's Disease
- Progressive Supranuclear Palsy
- Creutzfeldt-Jakob Disease (CJD)
- HIV dementia.

A breakdown of the approximate distribution of the different types of dementia is shown at Table 2.

Table 2: Proportions of types of dementia

Type of dementia	% (of people with a dementia)
Alzheimer's disease	62%
Vascular dementia	17%
Mixed dementia	10%
Dementia with Lewy bodies	4%
Fronto -temporal dementia	2%
Parkinson's dementia	2%
Other dementias	3%

1.5.2 Diagnosis

Typically, when there are concerns about a person's memory, they will be referred by their GP to their local Memory Clinic. These clinics usually form part of Community Mental Health Teams for Older Adults, though in some areas of the UK dedicated Memory Teams operate. Memory Clinics will conduct a series of cognitive assessments, and physical assessments (such as CT scans) if resources allow. This helps to establish a baseline, and sometimes obvious causes can be discovered (e.g. significant vascular damage or atrophy). Diagnosis is more often made after a series of assessments, where a pattern of deterioration is noted over time. In younger people, a probable diagnosis can be made on the basis of tests carried out which show marked atrophy or loss of abilities.

Although diagnostic pathways have improved markedly in recent years (Alzheimer's Society, 2012), it is still difficult to arrive at a speedy diagnosis, due to the nature of the condition (Welsh Assembly Government, 2011). However, early diagnosis can

maximise the potential benefits of early access to specialist therapies and support (Corner & Bond, 2004).

Common worries about receiving a diagnosis may include social concerns, such as fear of others finding out, or social embarrassment, and of long term dependency needs and loss of respect from others (Husband, 2000). Anxiety about receiving a diagnosis may be understandable, but has nevertheless been construed as catastrophising dementia (Jones, 1995). Prevailing anxiety may lead to hypervigilance for evidence of cognitive failures, social withdrawal, low self-esteem, self-stigmatization and thus impaired quality of life (Jones, 1995).

Some diseases may present dementia-like symptoms but may be treatable, such as meningoencephalitis (Ishihara *et al.* 2011). Such diseases, or conditions such as depression or infection, can respond to therapy, and therefore should continue to be considered as differential diagnoses, especially where there are atypical clinical features. It has been suggested that techniques such as neuroradiological examination may contribute to the diagnosis of dementia in younger people (Ishihara *et al.* 2011).

1.6 Young onset dementia

1.6.1 Epidemiology of young onset dementia

The definition of young onset dementia as being under the age of 65 is acknowledged as being arbitrary and reflective of cultural views of the onset of “old age” (Cox & Keady, 1999; McErlean, 2001). Despite this, services continue to use this age as delineation, reflecting the current and historical divide between ‘working age’ and ‘old age’. The division does, however, serve to highlight some substantial differences between younger and older age groups. For example, a younger person may be more likely to experience personality changes primarily, and there may be a faster rate of decline (Mungas *et al.* 2001). Young onset dementia may have a greater effect on speech, language and writing in its earlier stages, rather than on memory impairment (Harvey *et al.* 2003).

Although there are difficulties in diagnosing the early stages of dementia regardless of age, differential diagnosis of a dementia may be more difficult for younger people

than for older people, and can result in longer delays in diagnosis (Luscombe *et al.* 1998). Early symptoms can mimic depression, or be complicated by substance use, other physical or mental illness, infections, nutrition, poisoning, traumatic brain injuries, or space-occupying lesions such as a tumour (Cox & Keady, 1999). Different profiles of impairment may also be seen in younger people than in older people, and visuo-spatial functioning, attention and executive functioning are more likely to be impaired, rather than memory (Smits *et al.* 2011). This may mean that a younger person is able to present relatively well on a daily basis and to services, and may be able to compensate for their impairments to an extent (McMurtray, 2006).

Mood disturbances, particularly depression, agitation, elation, and irritability, may be early signs of cognitive decline in younger people (Ebner *et al.* 2010). There may also be a high frequency of psychiatric features and non-cognitive symptoms in early stages for younger people, which could aid clinicians in distinguishing people who require a more extensive evaluation for dementia (Kelley *et al.* 2009). However, the cognitive neuropsychology testing typically used in memory clinics is often not sensitive enough to detect the more subtle changes which may be sensed in a younger person with dementia (Oksengard & Winblad, 2004). One study found that a surprisingly high proportion of patients below the age of 65 displayed cognitive impairments on testing, but this appeared to be apportioned to causes such as head trauma, alcohol abuse, and HIV (McMurtray *et al.* 2006). It has been suggested that additional factors should be investigated, such as memory and recall, illness onset, emotional and mood lability, sleep patterns, and coping mechanisms (Chaifetz & Killian, 1983).

Although the exact causes are mostly unclear, some factors appear to increase the risk of developing dementia at a younger age, such as stroke (Alladi *et al.* 2011), hysterectomy at a relatively young age (Phung *et al.* 2008), heavy alcohol use (Withall & Draper, 2010), and illness factors such as HIV and neurosyphilis (Alzheimer's Society, 2012).

There is mixed evidence for the impact of a young onset dementia on life expectancy following a diagnosis. One large scale longitudinal study found almost double the life expectancy than for an older person diagnosed with dementia. However the reasons for this were unclear, and were suggested as being partly due to better physical health in the younger aged sample (Xie *et al.* 2008). However, another study found

that patients with young onset dementia had a far higher mortality risk than for those with late onset dementia, even after correction for age and type of dementia (Koedam *et al.* 2008), but explanation for this remains unclear.

1.6.2 Specific impact of a young onset dementia

The majority of the literature on the impact of a dementia is primarily focused on the effects of a dementia on the spouse or carer, or the children of someone with a dementia, however there are specific issues and needs relating to younger people that are particularly poignant. This includes financial worries, a sense of loss, and a sense of isolation from social contacts and from services mainly geared towards older people (Harris *et al.* 2006; Williams *et al.* 2001).

Although the symptoms of dementia may be similar, whatever a person's age, younger people with dementia may have different and more complex needs. People under 65 years of age are more likely to have dependent children and financial and work commitments which may be jeopardised by the onset of dementia. They may find it more difficult to rationalise losing skills at such a young age, and to access appropriate information and support (Alzheimer's Society, 2002). Some younger people with dementia find themselves especially stigmatised due to lack of understanding related to the relative rarity of the condition (Aminzadeh *et al.* 2007). Issues of loss of control and changes in personality throughout the process of a dementia may also be factors involved in the experience, especially pertinent in young onset dementia when these are often the primary features at earlier stages. Particularly, younger people may still have expectations of a long life up to and beyond retirement, and plans and ambitions still to fulfil (Alzheimer's Society, 2002).

The impact of a young onset dementia can be extensive and wide ranging. People with young onset dementia are more vulnerable to negative societal and health care-related effects of dementia (Alzheimer's Society, 2002). They may find it difficult to access health care benefits and community-based services, experience loneliness and isolation; and they may be more physically healthy and active, leading to difficulties in meeting safety needs (Aminzadeh *et al.* 2007). It is also likely that there may be challenges in finding appropriate long-term care placements, and this may cause great difficulties for caregivers (Rose *et al.* 2010).

In addition, people with young onset dementia may be more likely to be admitted to hospital, in comparison to those with late onset dementia. Some factors contributing to this may include high rates of alcohol-related dementia, and other types of dementia with physical comorbidity (e.g. Parkinson's dementia or HIV dementia). There may also be a greater incidence of behavioural disturbances. However, the reasons for prolonged length of stay and increased rates of hospitalisation in young onset dementia are unclear from the current literature (Draper, Gibson *et al.* 2010), but nevertheless may impose a greater burden on healthcare resources.

Younger people may be affected by rarer forms of dementia that can create various kinds of impairment in the individual. Although memory can be affected, such differing symptoms as personality changes, visuospatial and semantic tasks may have extensive personal and societal implications for the entire family (Roach *et al.* 2008).

The drive towards early diagnosis in younger people must be balanced alongside appropriate sensitivity. There is a high risk of misdiagnosis, given the high rate of overlap between symptoms and the relative rarity of dementia in younger people (Davies & Lerner, 2009). There may be an increased risk of suicidal ideation in younger people if they are not sufficiently prepared to receive such a diagnosis, or if it is made hastily (Draper, Pesiah *et al.* 2010).

1.6.3 Service issues for younger people

Historically, care of people under the age of 65 with a dementia was often difficult to meet in working age adult services or in older age mental health services (Williams *et al.* 2001). Older people's dementia services would not be accessible until people had passed the age of 65, and adult mental health services do not generally accept someone with a diagnosis of dementia, nor are they set up to cater for the needs of someone with dementia. Those in need of ongoing care may go to older people's inpatient services, to find that the only services that are available in fact cater for those significantly older than themselves. This situation has been long standing and several studies have recommended more age-appropriate, flexible and tailored services for dementia for some time (Alzheimer's Society, 2002; Barber, 1997; McErlean, 2001; Quinn, 1996; Sperlinger & Furst, 1994).

The relative rarity of young onset dementia may raise the question as to why younger people with dementia should receive specialist resources. However, it has been acknowledged that higher levels of intervention are often required by a younger person affected by dementia and their family (Bentham & La Fontaine, 2008). In terms of living with a dementia, younger people face very different societal challenges than older people (Cox & Keady, 1999). Older people may find that a diagnosis of dementia is more 'expected' for them and seen as a natural part of ageing (Hart & Semple, 1990), whereas younger people may be seen as having more productive value in society and in their immediate families, thus making the difficulties associated with a dementia even more pronounced (Cox & Keady, 1999).

The immense and worldwide improvement in health, and resultant longer life expectancies, may have far-reaching but perhaps under-recognised implications for mental health professionals and services. The nature of psychological issues encountered by clinicians may also evolve - for example, there may be increased retirement and leisure time, and higher expectations of greater health and productivity in later life. The increased sophistication of these expectations from current generations in terms of health care will lead to higher demands placed on physical and mental health services (Laidlaw & Pachana, 2009).

1.7 Treatment of Dementia

Since dementia is not curable, treatment may focus on management of symptoms attributable to the dementia (Baldwin & Murray, 2003). Treatment may also constitute regular monitoring of the progression of the dementia, management of pain, and consideration of the person's environment (Kitwood, 1993).

1.7.1 Medical approaches

Historically, some behavioural symptoms in later stage dementia, such as agitation, aggression or wandering, were managed by use of sedative or antipsychotic medication, to decrease risk of associated danger to the person (Eimer, 1989; Knapp & Prince, 1997). Currently, the main approach to treatment for AD is to prescribe acetylcholinesterase inhibitor, or "anti-dementia" medication, which may slow the progression of the disease, although it does not have a curative effect (Burns & O'Brien, 2006). The most commonly prescribed types include Donepezil, known by

its brand name “Aricept”, and Rivastigmine, known by its brand name “Exelon”. Anti-dementia medication is currently prescribed for the treatment of mild to moderate dementia, according to the decision of the clinician involved in assessment and treatment (NICE, 2011). However, such medication may not be beneficial for some people or for types of dementia other than Alzheimer’s disease.

1.7.2 Psychological approaches

A number of psychological interventions have been shown to be effective in helping people with some symptoms of dementia. These include:

- Cognitive rehabilitation, which may involve psychoeducation, mood management, psychological support, communication and development of practical skills (Wilson & Gracey, 2009).
- Validation therapy, based on the general principle of acceptance of the reality and personal truth of another’s experience, incorporates a range of specific techniques. However, there is currently mixed evidence for the effectiveness of this form of treatment in dementia (Neal & Barton-Wright, 2009).
- Narrative therapy, including Reminiscence therapy, designed to encourage patients to undertake life reviews by creative means, has been shown to reduce the incidence of depression in people with dementia (Bohlmeijer *et al.* 2005; Caldwell, 2005; Hsieh & Wang, 2005; Woods *et al.* 2009).

Other therapies, such as arts therapies, also show benefits when used in the treatment of dementia. One study described eight themes from 17 participants about the impact of such therapies on their quality of life: feeling content, importance of relationships, choosing an attitude for living on, and feeling worthy, wishes for freedom amid restrictions, living with loss, struggles with thinking and communicating, and persisting with life patterns. (Jonas-Simpson & Mitchell, 2005).

However, such treatment approaches have been reviewed mainly for use with older people (Woods *et al.* 2009). Psychological approaches such as reminiscence therapy have usually been designed with older people in mind, with resources appropriate to them. Therapies with relevance to younger people have not been widely administered or studied due to the relative newness of the approaches (Woods *et al.* 2009).

1.8 Caregiving in dementia

Caregiving may be defined as performing supportive tasks beyond those expected in mutual exchanges between adults (Graham, 1983; Twigg & Atkin, 1996). It may encompass a taking over of responsibility from a feeling of concern for the wellbeing of others (Cox & Keady, 1999; Graham, 1983). The spouse is often the person who takes on this role when their partner develops a health problem, and someone with a dementia may remain physically active for some time after diagnosis. A large proportion of people with dementia are cared for by a spouse or family member (Alzheimer's Society, 2012). Although it is recognised that family carers of people with dementia save the UK over £6 billion a year, the current financial cost of dementia to the UK is estimated to be £23 billion, including medical costs, long term care, and lost productivity of the caregivers (Alzheimer's Society, 2002; Chang & Johnson, 2012; Welsh Assembly Government, 2011).

Symptoms such as delusional thinking, activity disturbances and aggressiveness in dementia are more likely to be rated as troublesome to the caregiver (Shaji *et al.* 2009). The spouse in this situation is likely to, over time, suffer stress and often depression, anxiety, and exhaustion (Kaiser & Panegyres, 2007, Weuve *et al.* 2000). In particular, the diagnosis of young onset dementia has a significant impact on spouses, characterized by concerns of dependency, fear, and increased depression, especially where the dementia leads to substantial behavioural or personality symptoms (Kaiser & Panegyres, 2007).

Factors affecting the ability of caregivers to cope include their attributions of stress and burden. Such attributions are not solely reliant on the degree of cognitive impairment of the person they are caring for, but may be dependent on their perception of lifestyle change (Richards *et al.* 2003). Lazarus & Folkman's (1984) model has been used to explore caregiver burden in spouses of a person with dementia, and likewise finding that the caregiver's appraisal of stress is the primary predictor of their coping ability (Grael & Abbado, 2011). High perception of vulnerability, and low resources in terms of coping ability and social support, may also predict higher burden in spouse caregivers of a person with AD (Vitaliano, 1991). Caregivers of people with young onset dementia have also reported greater perceived difficulties due to behavioural disturbances when compared to caregivers of those with later onset dementia (Cox & Keady, 1999). It is suggested that

additional resources, such as care services, should be provided for sufferers of young onset dementia, in order to allow family caregivers to cope with difficulties associated with patient behavioural problems (Arai *et al.* 2007).

Other factors, such as gender, may also be important; for example, the caring role may be more implicit in female roles than in male, so that male carers may find the caring role more difficult to adjust to than do female carers (Dalley, 1996; Graham, 1983).

A high proportion of younger caregivers have reported stress in relation to employment and financial worries (Luscombe *et al.* 1998). Many caregivers also have to give up working before they had intended to, to take on their new role as carer for their spouse (Alzheimer's Society, 2012; Luscombe *et al.* 1998). Social support is the strongest predictor of good adjustment for younger carers, with coping strategies and choice in caregiving being weaker predictors of adjustment. Stress appraisal has been found to be unrelated to adjustment (Pakenham *et al.* 2007).

These studies suggest that carers of younger people with dementia do experience greater negative outcomes than carers of older people with dementia (Svanberg *et al.* 2011). However, the views of the individual with dementia may differ from those of their carers; the person with dementia may not be aware of negative outcomes, or carers may try to disguise their stress or dissatisfaction (Beattie *et al.* 2004).

Nevertheless, there is some evidence to suggest that caregiver stress may be ameliorated by the use of positive coping strategies, such as information seeking, and problem solving approaches (Aminzadeh *et al.* 2007). Support groups and cognitive behaviour therapy have also shown to have some benefit to caregivers in reducing caregiver burden (Weuve *et al.* 2000).

1.9 Services for young onset dementia

Although the number of specialist dementia services and projects for younger people in the UK is growing, provision is still inconsistent and there is still a general lack of age-appropriate support (Alzheimer's Society, 2012; SCIE, 2012). Younger people with dementia may also need input from specialist services such as genetic counsellors and substance misuse services, since they may be more likely to be affected by a hereditary condition or have other co-morbid difficulties (SCIE, 2012).

Recommendations for services have included the provision of broad-based care as well as assessment; clear communication about diagnosis and care; continuing peer support groups; easy availability of staff; professional staff behaviour; inclusion of people with young-onset dementia and their carers; and strategies to manage those with subjective memory impairment but no objective deficits (Willis *et al.* 2009).

There has been some debate within services and the third (voluntary) sector about the issue of resources for young onset dementia. The rate of dementia in people aged 75 and over is far higher than in people aged 65 and under. Yet, specialist funding has been provided to support younger people. Campaigners for older people have suggested that this may be a further example of an ageist bias, whereby older people receive fewer resources and services, and that younger people may be more vocal than older people in requesting services. However, it has also been acknowledged that older people's services have been well developed for some time and that the different issues faced by younger people with dementia do require different services (Baldwin & Murray, 2003; Kopelman & Crawford, 1996; Williams *et al.* 2001).

Although there are difficulties in diagnosing younger people with dementia, Memory Clinics remain a vital part of the diagnostic process. Their role may also be wider in focus for younger people, and in dealing with large numbers of non-dementia cases. One study found that they provide a valuable screening service (Kopelman & Crawford, 1996). In this study, a survey of case notes and correspondence from 200 attenders at a memory clinic was conducted to assess diagnoses, referral, outcome, and placement at discharge. The mean age of the sample was 43.7 years, with a diagnosis of dementia in only 13%. Over half of the sample showed organic memory or cognitive impairment, and depression was diagnosed in almost half the cases. Triggers to a referral were identifiable in over half of the sample, including failure to cope at work, marital or relationship problems, and offences or compensation cases. It was concluded that, within adult neurological and neuropsychiatric services, memory clinics might particularly serve younger groups for whom assessment and rehabilitation services are often poor. Memory clinics are also well placed to identify cognitive impairment caused by treatable conditions rather than dementia (Hejl & Waldemar, 2002).

1.10 Policies and Guidelines

A number of national policies guide the provision of dementia services in the UK:

- National Dementia Strategy – Living Well with Dementia (Department of Health, 2009).
- National Institute for Health and Clinical Excellence Clinical Guideline 42: Supporting people with dementia and their carers in health and social care (2006, amended 2011).
- National Service Framework for Older People (Department of Health, 2001): This is a 10 year programme seeking to link services, with the aim of supporting independence and health, via specialist services for key conditions and culture change towards attitudes of respect, dignity and fairness towards older people and their carers.
- ‘Dementia – Out of the shadows’, a report by the Alzheimer’s Society (2008).
- Royal College of Psychiatrists College Report 135 - Services for younger people with Alzheimer’s disease and other dementias (2006).

In Wales specifically, the document “National Dementia Vision for Wales – Dementia Supportive Communities” was developed jointly by the Welsh Assembly Government and the Alzheimer’s Society (2011). Recommendations included some key elements for developing Dementia Supportive Communities within Wales:

- People affected by dementia should have a voice;
- The community is consulted and listened to;
- Available services are accessible and responsive to the needs of the community they seek to serve;
- People with dementia are included in community activities, and they and their carers are supported by that community.

(Welsh Assembly Government & Alzheimer’s Society, 2011).

1.11 Coping and adjustment

The term “psychological adjustment” has been used in previous literature to refer to “a process of becoming accustomed to a new situation” (Pearsall, 1999). This process necessitates a series of interactions and adjustments between the person and the environment. Difficulties within the process of adjustment can result in stress. Stress has been defined as “the condition that results when the person / environment transactions lead the individual to perceive a discrepancy - whether real or not - between the demands of a situation and the resources of the person’s biological, psychological, or social systems” (Lazarus & Folkman, 1984). However, stress in this context is not seen as a stimulus or a response, but rather as a process in itself. The person suffering stress is seen as an active agent who can influence the impact of a stressor through behavioural, cognitive and emotional strategies.

According to the Lazarus & Folkman (1984) model, the cognitive appraisal of stress can be seen as a mental process by which a person assesses (1) Whether a demand threatens their wellbeing, and (2) Whether they have the resources to meet the demand of the stressor. This may happen in two stages of appraisal - primary and secondary.

During the primary appraisal stage, a person will be seeking to understand the the meaning of the situation as it affects their wellbeing. One of three types of appraisals might come of this meaning-making: “It is irrelevant”; “It is positive (or benign)”; or “It is stressful”. If it is seen as stressful, then further appraisal is made of possible implications:

- Harm-loss – considering the amount of damage that has already occurred, for example an injury, its seriousness and whether that is exaggerated;
- Threat – can be defined as the expectation or fear of future harm. A great deal of stress results from appraisals that involve harm-loss and threat.
- Challenge - a way of viewing or reframing the stress in a positive way.

Secondary appraisals occur at the same time as primary appraisals, and relate to the appraisal of one’s own resources relating to the problem at hand. Examples may include feelings of not being able to deal with the problem.

This model of coping is viewed as a process over time (Lazarus & Folkman, 1984), and acknowledges that constant reappraisals will occur.

Appraisals of coping efficacy may be particularly important predictors of psychological adjustment (Cummings *et al.* 1994; Zautra & Wrabetz, 1991). Coping efficacy may be described as the subjective assessments of whether or not coping efforts are likely to be successful in meeting one's goals within the context of a specific stressor (Aldwin & Revenson, 1987). Perceptions of efficacy in coping are associated with reductions in psychological distress (Aldwin & Revenson, 1987; Zautra & Wrabetz, 1991). Such perceptions also interact with specific coping efforts in predicting psychological distress and well-being (Aldwin & Revenson, 1987; McCrae & Costa, 1986; Zautra & Wrabetz, 1991). Coping efforts promote well-being or reduce psychological distress, depending on the type of coping used and the individual's perception of its effectiveness.

Zautra and Wrabetz (1991) found that positive appraisals of coping with a negative health change were related to less distress for respondents who reported using "active" coping efforts. These efforts included seeking support, taking action, and emotional expression. Another study found that participants perceived highest effectiveness when using problem-focused coping responses and emotional expression (McCrae and Costa, 1986). Moreover, the use of coping efforts that were perceived to be effective, and the avoidance of those perceived to be ineffective, may contribute to psychological well-being (Gottlieb & Rooney, 2004).

1.11.1 Coping with dementia

There has been little research examining how sufferers of dementia cope with the changes and demands. However, some factors are suggested to contribute to adjustment to dementia, including: the person's individual views about illness; their experiences of losses resulting in frustration and uncertainty; and adaptation to a new role in relationships with family and friends (Mok *et al.* 2007). A feeling of control and autonomy is seen as a strong factor in other literature, and in particular the cognitive control of events or situations. For someone with dementia, retaining a sense of control is linked to a lower appraisal of stress (Miller, 1979; Roth & Cohen, 1986).

It is important to recognise that coping and adjustment are not solely related to subjective appraisals. With the progression of dementia, cognitive functions will steadily decline, but other stressful behavioural symptoms may peak and fluctuate at various stages of dementia. For example, self-care deficits begin early in dementia and increase with dementia severity, but many distressing behavioural symptoms, such as aggression, tend to decrease in later stages of dementia. These fluctuations should also be taken into account when supporting sufferers and caregivers (Haley & Pardo, 1989).

1.11.2 Coping with dementia in families

Some research has focused on coping as a family member of a person with dementia. The temporal model (Keady & Nolan, 2003; Wilson, 1989) of process and coping in family carers of AD, sets out eight stages. The first is 'Noticing', followed by any unusual behaviour as being 'Discounted' and 'Normalised'. 'Suspecting' follows, usually from a trigger event, and then 'Searching for explanations'. 'Recasting' and 'Taking it on' follow a process of admittance, then 'Going through it' and 'Turning it over' constitute the stages of acceptance. This model has been used as a way of understanding processes of adjustment within families of younger people with dementia (Keady & Nolan, 2003).

Where a parent has young onset dementia, it is likely that their children will suffer psychological or emotional problems as a consequence, particularly in relation to an uncertain future (Svanberg *et al.* 2010). The stress-process model of coping in caregiving may have distinctive features relating to the interaction of young onset dementia and the developmental stage of families involved (Allen *et al.* 2009).

One model of adaptation applicable to children of a parent with dementia was developed by Svanberg *et al.* (2010). In this grounded theory study, four categories within the process were identified: discovering dementia; developing a new relationship; learning to live with it and going through it together. More than half of the participants showed high levels of burden, and most showed moderate levels of resilience. A three-stage process model was then proposed, with children moving through grief to emotional detachment and increased maturity.

It has been suggested that the context of caring for a dementia patient may allow family members to break down their efficacy appraisals by relating them to specific

coping goals. For example, aspects may include efficacy in meeting the demands of personal care, managing distressing cognitive and behavioural symptoms, sustaining a sense of competence and self-worth, and regulating their ever changing interactions with their relative (Gignac & Gottlieb, 1996).

1.11.3 Coping with dementia in couples

Much of the research that has examined the role of coping in the context of caregiving has been guided by Lazarus & Folkman's (1984) model (Pakenham *et al.* 2007). However, most of this research is based on the premise that adjustment to illness and caregiving is determined by the context, and is mediated by appraisal, coping strategies and coping resources (Goode *et al.* 1998; Pakenham *et al.* 2007).

It has been suggested that a chronic illness affects the adjustment of both the patient and the spouse, so that coping strategies of the patient may be examined in relation to those of the spouse, and vice versa. This type of dyadic coping may differ through phases of the life span (Berg & Upchurch, 2007). Sociocultural factors such as culture and gender may affect the development of coping, as well as contextual factors such as the quality of the relationship and the progression and demands of the illness. This model may help to understand how couples coping with chronic illness may jointly appraise and cope, and determine when spousal involvement is beneficial or harmful to adjustment (Berg & Upchurch, 2007).

The onset of dementia places major demands on coping resources, and it becomes crucial for carers to develop adaptive coping strategies to optimise well-being and minimise strain (Clare, 2002). Coping strategies in this context can be seen as a continuum, running from self-protective to integrative responding, and include reactions, explanations, and emotional responses (Robinson *et al.* 2005). For example, one study of caregivers of a person with dementia found that self-protective strategies included holding on and compensating, reflecting attempts to maintain a sense of self and normality. Confrontational responses included "developing a fighting spirit", and coming to terms with the change; these constituted ways of attempting to integrate changes by seeing them as a challenge, and balancing struggle with acceptance. Most participants in this particular study were employing self-protective strategies, and the study suggested that support could facilitate the development of adaptive coping strategies (Clare, 2002).

Some studies have examined the ways in which caregivers of persons with dementia cope with these stressful demands (Pearlin *et al.* 1990; Pruchno & Kleban, 1993; Williamson & Schulz, 1993). In terms of the Lazarus & Folkman (1984) model, research into coping with dementia views it as a process that can moderate the impact of the psychological and emotional demands on caregivers. Coping responses perceived to be effective are associated with lower levels of caregiver depression and burden, and higher reported levels of life satisfaction and health (Gignac & Gottlieb, 2004). In a review of 16 studies, it was found that a general tendency towards problem-solving and acceptance styles of coping is likely to be advantageous to caregivers of people with dementia. However, it acknowledged that this understanding was at the present time unlikely to be able to influence clinical practice (Kneebone & Martin, 2003).

Support groups for sufferers and partners can fulfil an important role in bolstering couples' coping potential. One study found that a Memory Club for early stage dementia care can offer care partners the opportunity to plan, prepare, and increase coping skills in the face of early dementia progression (Gaugler *et al.* 2011). Where people have been able to adopt a positive outlook in this context, this may be due to receiving understanding, support and respect from family and friends as well as acceptance of the illness (Mok *et al.* 2007).

There is as yet little literature on the process of coping with dementia in couples under 65 years of age. However, coping and adjustment has been widely investigated in carers, looking at influencing factors such as social support. In terms of the couple relationship, younger people may have a longer duration of caring (Freyne *et al.* 1999). Considering the longer average duration of young onset dementia compared to later onset, lasting on average 3.4 years longer than for older people with dementia (Tindall & Manthorpe, 1997), this fatigue could partly account for higher perceptions of burden in carers of younger people with dementia. Combined with the more rapid progression of early onset dementias (Kaiser and Panegyres, 2007), distress can increase over a prolonged period of time (Svanberg *et al.* 2011).

1.12 Selected Literature Review

From the literature base described in Section 1.5, a selected review was conducted of papers particularly relevant to the current study. Papers were reviewed which matched the following criteria: (1) the sample included couples or patient-carer dyads; (2) aspects of coping were examined. The search demonstrated that there was a moderate amount of literature relating to young onset dementia and carers, though very little involving the person with dementia themselves. There were eight particularly relevant papers found to be suitable for review for the purposes of the current study. A summary table of these papers can be found at Appendix 2.

1.12.1 Description of papers reviewed

Of the papers reviewed, four had carried out qualitative interviews of couples (with samples of 9, 12, 28, and 30 couples). One had used qualitative self-report measures with younger people with dementia and carers separately (a total of 38 participants), one was a qualitative survey (with a total of 1116 participants), one was of mixed design utilising 49 couple participants, and one was a literature review of 26 papers which focused on the experiences of people with dementia and their families.

Most of the studies in this area have used small scale qualitative interview methodology. In one such study, Clare (2002) interviewed 12 couples aged between 57-83 years. Participants and their partners were interviewed separately, which could have reduced the potential response inhibition if couples are interviewed together, but could also increase the possibility of missed information from the person with dementia. This study used Interpretative Phenomenological Analysis (IPA) to analyse the data, and described different ways in which individuals attempt to adjust to memory problems. A continuum model was proposed, with coping responses ranging between self-protective to integrative. The sample was relatively large for a study of this type, although it only used participants with early stage AD who had undergone cognitive examinations at memory clinics. This could limit its generalisability in relation to the large estimated numbers of people who may not present to services. Similarly, a study using interviews from 9 couples ageing between 73 – 85 years (Robinson *et al.* (2005) used a family systems perspective and IPA to analyse the data. Focuses were on the couples' experiences and shared constructions of receiving a diagnosis of dementia. Participants were from memory

clinics in London, and all had mild or early stage dementia. Themes were generated within two categories of: “Not quite the same person, tell me what actually is wrong”, and “Everything’s changed, we have to go from there”. The authors constructed a cyclical model from the themes, describing processes whereby couples make sense of changes. Although this study was small and may have lacked cultural and socioeconomic diversity, the process and model described would seem to be very thoroughly investigated and analysed for the available sample. The findings of this paper would seem to have particular relevance to the scope of the current study.

Qualitative interview methodology with couples has been utilised in a longitudinal study (Ingebretsen & Solem, 1998). This study involved 28 couples, aged between 60 and 87, where one has dementia. Semi-structured interviews were carried out at an early stage of the process of diagnosis, followed by another interview every 6-9 months over 3 years. The findings focused how the experience of dementia can repeatedly challenge and change people’s usual coping strategies. The study also examined attachment behaviour by looking at caregivers’ expectations of their spouse, and identified three patterns of attachment behaviour through the emergence of a dementia. The authors suggested that people with secure attachment patterns, despite perhaps experiencing great losses because of the dementia, may find it easier to accept the changes and insecurity it brings. Although relatively large for a qualitative study, and with the advantage of longitudinal data, this study’s sample was exclusively Norwegian, which may limit generalisation to other cultures.

One paper made attempts to explore different cultural perspectives by using two qualitative data sets, from 23 younger people with dementia in the United States and from 15 families of younger people with dementia in the UK (Harris & Keady, 2004). The authors hoped to challenge the construction of dementia as an older person’s disease. This study generated themes around diagnosis, selfhood, relationships, work, social isolation and dependency. Conclusions were that younger onset dementia presented very different challenges due to the sufferers’ life stage, although it was acknowledged that there were many similarities with late onset dementia. The study used a varied methodology to obtain data, utilising a mixture of face to face interviews, focus groups and online interviews. Collecting the data in such differing ways may have partly addressed the difficulties that some participants may have, for example in feeling able to disclose their true feelings in a focus group or face to face interview. Another large study using varied methods of data collection (Aminzadeh *et*

al. 2007) involved 30 couples aged 65-85 in a day hospital setting, and used audio recordings of the diagnosis disclosure meeting, separate face to face interviews with patients and caregivers, focus group interviews with a sub-group of caregivers, and observations taken from clinical records. Participants with dementia had mild to moderate cognitive impairment. Emotional responses to the diagnosis were analysed, and information collected on lack of insight or denial of diagnosis, grief reactions to actual or anticipated losses associated with dementia, and positive coping responses. Stages of emotional response were linked to the temporal model of dementia (Keady & Nolan, 2003; Wilson, 1989). The authors stated that there was a need to understand the individual experience at the point of diagnosis, in order to maximise adaptive coping responses. This was one of the first studies to explore prospectively the impact of a dementia diagnosis, and suggested that the impact needs to be considered in planning a diagnosis disclosure. For example, the results showed that more negative reactions were observed to a diagnosis of AD than to vascular dementia, possibly reflecting differing levels of fear and stigma associated with the different diagnoses. However, the authors acknowledged that this needs to be validated by future research and explored in different settings.

Studies have used other methodologies to explore the issue of coping in dementia. Quantitative measures, such as used by Seiffer *et al.* (2005), have investigated lack of awareness of changes in cognitive and behavioural functioning. Using a cross-sectional correlational design, 49 individuals with dementia and their partners (aged 54-86 years) completed standardised self-report questionnaires to investigate personality factors and attitudes towards emotional expression, and the relation of these factors to people's coping strategies in managing the threat of dementia. Findings suggested that negative attitudes to emotional expression were predictive of avoidant coping responses in terms of changes resulting from a dementia. The sample was larger than the minimum required by a power analysis ($n=38$), making it a strong study. However, participants had varied types of dementia, meaning that symptoms and progression may have been quite different between participants. In addition, the study is based on self-report questionnaires, assuming that carers are responding accurately. The study does not take into account the impact of impaired cognitive functioning on questionnaire completion, but in its discussion does acknowledge this possibility.

A large scale telephone survey canvassed directly the views of people with AD and their carers (Kurz *et al.* (2008). A large sample of 502 sufferers and 614 carers were

surveyed in a variety of countries in Europe, Brazil and North America. Carers were aged 42 to 59, and sufferers were aged from 69 to 77. Responses differed between sufferers and carers; carers expressed more concerns about practical issues such as medication, and sufferers were more concerned about feeling safe and supported at home and their ability to enjoy life. Inclusion criteria were not stringent, to gain a large sample, and this may have resulted in some disparities between participants and between the country populations surveyed. The process by which participants were referred by their physicians may have also introduced some selection bias.

Broad inclusion criteria were also utilised in a systematic review carried out by Svanberg *et al.* (2011). Results of the review were divided by impact on the individual, impact on the family and children, and diagnostic difficulties. In comparing between those caring for younger and older people with dementia, it was found that carers of younger people reported significantly higher burden and difficulties related to behavioural problems. Although this was not related to the level of cognitive impairment, it may have been affected by differing types of behavioural disturbance. The wide range of study aims and methodologies contained in this review makes its scope quite general, but this may mean that key issues are difficult to determine.

1.12.2 Summary of review

The majority of the available literature focuses mainly on the experience and perspective of the caregiver, with few taking account of the perspective of persons with dementia. The selection of papers reviewed provides a small but important evidence base for exploring the topics from the perspectives of couples. An examination of how younger individuals and couples cope with this huge shift to their sense of self and life journey may help to understand how they and their families can be more effectively supported through this time.

1.13 Aims of the current study

The relevant research literature has highlighted the complex consequences of a dementia upon younger people and their partners. The importance of coping processes in circumstances such as dementia, in terms of psychological and psychosocial wellbeing, has also been highlighted. Significantly, the available evidence base relates mostly to older couples and to caregivers of people with dementia. There are also indications that a young onset dementia requires more

significant and more explicit processes of adjustment than those needed for older people and their carers.

The current study aims to explore the experience of young onset dementia, from the perspective of the individual and their partner. It will be important to discover more about the coping and psychological adjustment processes of younger couples when faced with a diagnosis of dementia. Beliefs and understanding of dementia may be important factors which affect the ability to cope with the related life changes, and which make it more or less likely that they will adjust successfully. Such beliefs and understanding may also affect their sense of self and relationships, and the likelihood that they will seek support. The current study will also explore the perspectives of professionals working in the field of young onset dementia, by seeking their views on coping processes used by couples, and factors which may influence their own ways of working. It is hoped that this will aid understanding of the needs of younger people and their partners and families as they adapt to life with a dementia.

This study will also seek to question the experience of service provision, including intervention and support prior to, during and post diagnosis, and what participants think could be improved upon.

1.13.1 Clinical relevance of this study

There is a large amount of literature on the experiences of, and support for, spouses and carers of people with dementia, the majority focusing on older adults. Thus, the views of people with dementia themselves are often assumed and are not based in evidence (Rodeheaver and Datan, 1988; Wilkinson, 2002). The literature covering people with dementia together with their partners is also very sparse, particularly relating to younger people with a dementia specifically coping with the process of adjustment following diagnosis. Understanding how people with early-stage dementia naturally attempt to adjust and cope is an important starting point in developing interventions that can enhance self-efficacy and adaptive coping (Clare, 2002).

Recent developments in policy and practice have emphasised inclusion, but dementia remains stigmatised in terms of social inclusion (Corner & Bond, 2004). This may be even more pronounced for younger people (Kaiser & Panegyres, 2007;

Wilkinson, 2002). There are some evidence-based models of intervention in working with dementia at different stages, however there is little evidence for the efficacy of these with younger people. Specific services for younger people are also still in the early stages of development.

It is therefore hoped that the findings of this study will be able to provide further information for service planning, and will contribute towards a greater understanding of the experience following a diagnosis of young onset dementia. The findings may also provide a contribution towards the development of interventions that are sensitive to the diversity and needs of younger people with dementia. It is hoped that services might be able to use this information as part of the diagnostic process for younger people, by assisting in identifying those who may benefit from extra support to aid their adjustment.

CHAPTER TWO: METHODOLOGY

2.1 Overview

The current study was designed in order to provide a greater understanding of the factors that contribute to psychological adjustment and coping in younger people with a dementia, and their partners. In order to investigate these factors, a qualitative design was utilised. Six couples and six professionals were recruited through a memory clinic in South Wales (“the clinic”). Semi structured interviews were conducted, in which aspects relating to the personal stories of the couple coping with dementia were discussed. This allowed the topics to be partly influenced by the participants. Interviews were digitally recorded and transcribed. The transcripts were analysed using IPA, which involved interpretation of the data by the researcher. Data were then collated into a series of themes to depict the meaning of the participants’ accounts.

The aim of this chapter is to outline the background to the study and the procedures involved, including the rationale for the methodology used. The methodological components of the study, specific procedures undertaken including the process of data analysis, and the characteristics of the participants will be described. The researcher’s position and the potential impact on the study will be considered.

2.2 Design

A qualitative research methodology was used in the design and analysis, using an interview-based research methodology. Semi-structured interviews were used to explore participants’ views of the following areas:

- The journey of diagnosis with young onset dementia;
- The meaning constructed by couples affected by young onset dementia, from both the perspectives of the couples and the professionals working with them;
- Ways in which individuals and couples coped with the life changes involved, exploring both positive and negative processes of adjustment.

2.2.1 Rationale for qualitative design

A qualitative methodology rather than quantitative was chosen for this study. Quantitative research is typically used to investigate phenomena that can be directly

observed and measured numerically (Coolican, 1999). Therefore, it inherently emphasises an objective and scientific approach, with the assumption that human experience is reducible to observable facts and mathematical relationships (Coolican, 1999). Qualitative methodologies emphasise meaning, and the sense that is made of phenomena or experiences, and include consideration of the researcher's personal perspective (Willig, 2008). Research using qualitative designs emphasises the attempts at understanding, based on the perspective of those being studied (Elliott *et al.* 1999).

As the researcher was interested in individual views and perspectives, the selection of a qualitative methodology was felt to be relevant and appropriate to seeking an understanding of specific experiences. The focus was on understanding some of the psychological processes involved in developing coping mechanisms for an unprecedented event in people's lives – in this case, having young onset dementia. Utilising a qualitative methodology facilitated development of an understanding of participants' experiences as told in their own voices, and did not simply focus on the researcher's own perspective (Carrick *et al.* 2001).

The methodology also took account of the importance of social interactions between the sufferer and their partner in their social world (Bryman, 2004). This enabled the study to include a consideration of the phenomena in the context of couple relationships, taking account of multiple perspectives.

The data collection method was a face to face qualitative interview. This methodology has been used in similar studies with dementia sufferers and their partners (e.g. Clare, 2002; Clare, 2003; Robinson *et al.* 2005). Interviews allowed for lengthier engagement with participants and provided rich portrayal of their feelings, emotions and experiences. This methodology also enabled flexibility and choice in terms of time and location of interview. This was important to the participants, since the couples still held a number of daily commitments, and had family lives. In some cases this flexibility allowed them to schedule an interview at a time where the sufferer would be less tired and at their best. The interviewer was also able to allow the participants to share their stories in a supported manner, and to offer to follow up if further support was felt to be required (Dickson-Swift *et al.* 2008).

2.2.2 Ensuring scientific quality and rigour in qualitative research

To ensure that this study employed an effective qualitative research methodology, the researcher aimed to follow the guidelines set out by Elliott *et al.* (1999). These guidelines outline good practice specifically for quality in qualitative research (Elliott *et al.* 1999):

1. Owning one's perspective. The researcher should communicate their own values and assumptions and the contribution of this to their understanding of the area of study. This allows the reader to consider the influence this might have had on the researcher's interpretation. In this case, the researcher's experience and interest is outlined in section 2.2.4. To help maintain objectivity, the researcher also sought supervision from qualified and training peers, and kept a reflective research diary, an extract of which can be found at Appendix 3.

2. Situating the sample. The participants' circumstances should be described, to allow consideration of the relevance of the findings. Participants are described in Section 2.5.5.

3. Grounding in examples. The reader can consider the accuracy of fit between the data and interpretations by way of examples of the data. Categories identified during the analysis are illustrated by the inclusion of direct quotes, in Chapter 3.

4. Providing credibility checks. In this study, the data analysis was checked by the researcher's academic and clinical supervisors, who have extensive knowledge of the methodology employed and the subject area. In addition, an iterative process was supported by a clinical psychologist working in the field.

5. Coherence. The interpretation should be presented with coherence and integration. This was checked by the supervisors of this study.

6. Accomplishing general vs. specific research tasks. The aims should be transparent. As this aim was to explore, rather than to generalise, IPA techniques were used, allowing systematic and comprehensive analysis of the data. There are naturally limitations to applying this methodology, which are discussed in Chapter 4.

7. Resonating with readers. This should be apparent, upon reading, by the ease of connection with the interpretation and the particular phenomena being studied. This aspect of the study was considered carefully by its supervisors.

Although there has been some debate within the literature about the usefulness of these criteria, including the challenge that they may be oversimplified or not widely applicable (Fade, 2003; Reicher, 2000), they remain the most widely used within psychological research for evaluating the quality of qualitative studies.

2.2.3 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (“IPA”) is an experiential qualitative approach to research in psychology and the human, health and social sciences. IPA is partly based on a branch of philosophical knowledge known as phenomenology, and was developed by Professor Jonathan Smith at Birkbeck University. The aim of IPA was to provide a methodology to understand “actual instances of life, not actuarial incidence” (Smith, 2006; Willig, 2008). Phenomenology aims to understand how human beings gain knowledge and understanding, and the ways in which the world is experienced by individuals (Willig, 2008). It assumes that perception is a primary element in psychological activity, along with individual presuppositions about self, other and the world (Garfinkel, 1967). It also emphasises the value of multiple and differing perspectives as a valid study focus (Barker *et al.* 2002).

IPA, rather than taking a general view, aims to explore the participant’s experience whilst taking account of the standpoint of the researcher (Lyons & Coyle, 2007; Willig, 2008). Through detailed engagement with the text, it allows the voice of those experiencing the phenomena to be heard alongside whatever evidence or literature may have come before. It is focused on the individual involved, and no attempt at comparison is made (Barker *et al.* 2002). IPA would seem particularly relevant in this subject area, where the voices of individuals with dementia are often omitted in research (Wilkinson, 2002).

IPA, as well as focusing on experiences and perceptions, also recognises the role of the researcher making sense of these accounts at an interpretative and psychological level (Smith & Osborn, 2003). A two-tiered interpretation process is

involved, namely, the researcher tries to understand the participants' experience, via the participant's attempts to make sense of their experience.

Some key characteristics distinguish IPA methodology from other qualitative methods. Principally, its idiographic nature means that one continues with detailed examination of each case until a level of closure is achieved. This case by case analysis enables the researcher to examine each for similarities and differences. IPA also provides a flexible technique, to allow unexpected topics and themes to emerge both at interview and analysis. This is enabled by broad research and interview questions. IPA then allows the researcher to relate the findings to existing literature, rather than discussing them in isolation (Willig, 2008).

Another, more philosophical, advantage of IPA is that it draws on positive approaches to psychology (Seligman & Csikszentmihalyi, 2000). Thus, it offers flexibility to take a less disease- and deficit-focused approach, and gives participants a chance to express their views about strength, wellness and quality of life (Reid *et al.* 2005).

Other methods of analysis were considered. For example, the Grounded Theory method would explicitly examine a particular process (Lyons & Coyle, 2007; Willig, 2008). However, since the aim of the current study was to understand the experiences rather than explain them, and the analysis will focus on understanding an experience and capturing its meaning, it was felt that IPA would be the most appropriate methodology for this study.

IPA, although typically used for analysing individual interviews, has also been used in joint (couple) interviews (Robinson *et al.* 2005). In this instance it offers a methodology for analysing a shared experience as a single unit of data (Robinson *et al.* 2005).

2.2.4 Acknowledging the researcher's position

The researcher can be defined as an instrument in qualitative research due to their inevitable effect on the process of investigation (Denscombe, 2007). It is therefore acknowledged that the values and assumptions of the researcher are an important factor that may affect the study (Elliott *et al.* 1999). This section aims to outline the potential influences on the researcher.

The researcher was a final year Doctoral trainee in Clinical Psychology and had previously worked in a memory clinic. This work had included involvement in cognitive assessments and therapeutic groups with younger people with suspected or diagnosed dementias. The experience sparked an interest in the area and an awareness of the qualitative differences between such early onset cases and older adults with dementia. This interest was later brought into focus by a strategic development of specific resources for young onset dementia in the area. Discussions with a Consultant Clinical Psychologist involved in the service development helped to generate and expand the idea for this study.

The researcher was aware that many authors in the field recommended the inclusion of people with dementia themselves for research (Wilkinson, 2002). In addition, the researcher consulted a charity which advocates for the rights of people with dementia, which further encouraged the researcher to conduct a study including people with dementia themselves.

During the process of the study, the researcher made every effort to maintain awareness of any preconceptions and presumptions about younger people with dementia. The researcher felt confident in clinical interviewing skills, but was less experienced in research interviews. Thus, it was important to maintain an awareness of the nature of these particular interviews.

The researcher's knowledge and experience of the subject area was felt to be beneficial for allowing the participants to disclose their personal experiences and feelings. In addition, the fact that the researcher was not a part of the memory clinic allowed the participants to feel freely able to express their opinions about their treatment.

The researcher had not had personal experience of a relative or friend with young onset dementia, and did not know any of the participants prior to conducting the interviews. The researcher maintained a reflective diary throughout the process, in order to identify factors that may identify findings and to reflect on the decisions made. Extracts from this diary can be found at Appendix 3, and illustrate the development of thinking about the study through the research process.

2.2.5 Consultation

Additional input is recommended during the process of developing a research study, to generate wider views on the relevant ideas and format (Barker *et al.* 2002). In seeking this input, several discussions were held with clinical and academic supervisors. The researcher also discussed ideas with clinicians at the clinic, a young onset dementia service, and the local branch of the Alzheimer's Society. The researcher attended two conferences, both of which featured presentations by a number of key figures in the field of dementia research and policy.

Service User Consultation

In conjunction with staff at the clinic, a consultation was arranged with two service users and their spouses, who volunteered to take part. The consultation focused on the content of the research and advice was sought as to terms used, structure of interviews, and whether spouses should be invited. One point that was raised strongly by the couples consulted was that of terminology used in the study paperwork. It was felt that the use of the term 'dementia' itself should be avoided, since many of those affected by it dislike the term, instead identifying with terms such as 'memory difficulties'. It was also strongly felt that interviews should be held with couples together, rather than with individuals, in order to gain an understanding of the shared experience and to avoid missing vital parts of information that may not be remembered.

The researcher acted on this advice as much as possible in constructing and carrying out the study. However, the Ethical Review of the study clarified the need to use the term 'dementia' in the paperwork, details of which are discussed in Section 2.3.2.

2.3 Ethical Considerations

A number of ethical concerns were present in the conceptualisation and design of this research. Primarily, there were risks inherent in asking vulnerable individuals to disclose personal stories. Every effort was made to make the process as emotionally safe as possible for participants. The researcher gave unlimited opportunities for participants to withdraw at any point.

2.3.1 Research and Development

An application was sent to the Cardiff and Vale University Health Board Research and Development for scrutiny of the scientific and ethical soundness of the study. The outcome of this review can be found in Appendix 4.

2.3.2 Ethical Review

An application for full ethical review of the study was sent to the Dyfed Powys Research Ethics Committee (“REC”), who gave careful consideration to the study. At initial review, concerns they raised were regarding the provision of fully informed consent, with regard to the use of the term ‘memory difficulties’ in the study paperwork. It was explained that during the early stages of development of the study, it was thought that couple participants should be protected from the term ‘dementia’ in paperwork. However, it was felt by the REC that this might impede the fully informed consent of participants, and they requested that all terms be changed to ‘dementia’ in the study paperwork to reflect this.

It was also requested that letters be sent to the couple participants’ General Practitioners (“GPs”). This had not previously been considered by the researcher, however the REC felt that should participants feel distressed or concerned following a research interview, they may decide to access their GPs for support, and it was important that the GPs were aware of their participation.

Following these amendments, the study was given a favourable opinion by the REC (Appendix 5).

2.3.3 Capacity and Informed Consent

Mental capacity is an important concept in clinical decision making in mental health, and is governed by the framework of the Mental Capacity Act 2005 (Department of Constitutional Affairs, 2007). The Mental Capacity Act states that a person is deemed to have capacity to make a decision, unless there is “an impairment or disturbance of mental functioning (such as an intellectual disability, dementia or other cognitive impairment, acquired brain injury or mental illness) and this impairment is sufficient to affect their capacity to make a particular decision” (Church & Watts,

2007). If a person has an impairment, a four step process should be used to assess their ability to make the specific decision required, at the time the decision is required. The person needs to demonstrate that they:

- understand the information relevant to the decision
- can retain the information for the period required to make the decision
- can weigh the information, including the ability to see both sides, and can make a decision one way or the other
- can communicate their decision by talking, using sign language or another form of communication understood by others (British Medical Association & Law Society, 2004; British Psychological Society, 2006; Church & Watts, 2007).

The framework of the Mental Capacity Act 2005 was used to assess the capacity of potential and actual participants throughout the process of recruitment and participation. The assumption of capacity is the overriding principle of the Mental Capacity Act. However, since a dementia can potentially affect the ability to make an informed decision, where memory clinic staff wished to suggest participation to a patient, they needed to first conduct an assessment of their ability to consent to participate. The participants would also need to be able to demonstrate their capacity at the time of interview; the researcher had experience in using the tenets of the Mental Capacity Act, and was able to evaluate the capacity of participants for the purpose of the study prior to beginning the interview.

Consent was obtained verbally from all participants, over the telephone and again in person before conducting the research interviews. Consent was also obtained in writing, using a signed and initialled consent form which all participants completed before commencement of the interview. Separate consent forms were prepared for sufferers, partners and professionals (Appendices 7, 8 and 9).

To assist in facilitating their decision, all participants were provided with a written participant information sheet (Appendices 10 and 11). They were also provided with contact details for the researcher and supervisors, and had opportunities on the telephone and at interview to ask questions and to withdraw from the study.

Consent was also given for the researcher to send separate letters to the GPs of each sufferer and partner (Appendix 6), which was done after arrangement of the interview but before the interview was carried out.

Prior to interviews being conducted, the information sheet was revisited and salient features were reiterated to participants. In particular, participants' ability to withdraw at any point, without consequence for their clinical care, was emphasised throughout.

Had any participant been unable to provide written informed consent, or if the researcher had any concern about their ability to do so, it would have been explained that they were unable to participate in the study.

2.3.4 Confidentiality

The privacy of all participants, as well as those who declined to participate, was protected by the procedure, which determined that only staff at the clinic would be involved in contacting potential participants and therefore only they would know who had been approached. Contact information for the participants who expressed an interest in taking part would be disclosed by the participants themselves, by choosing to sending a reply slip to the researcher.

The confidentiality of information about participants was ensured in several ways. The researcher was provided only with contact information of interested parties, and had no access to medical or other notes or files. Contact information and other identifiable information, such as completed consent forms, was immediately stored separately from the data. The digital recordings were stored with coding and, following transcription, immediately deleted. All transcriptions were coded. Although detailed descriptive information and quotes were used in the final write-up, identifiable information such as names was changed and pseudonyms were used throughout.

It was explained to participants that any information they provided would remain confidential and would not be passed to the clinic or to any other party. A stated exception was if the researcher had any concerns about any of the participants, and it was agreed that in such cases the concerns would be reported to the clinic. However, no such causes for concern arose during any part of the research process.

2.3.5 Other Ethical Considerations

Participants in this study with a dementia were considered to be particularly vulnerable, since they were all subject to a degree of cognitive impairment. Particular care was given to ensuring capacity to consent in this regard. It was also recognised as important to consider the capacity and potential vulnerability of the partners.

It was acknowledged that the topic area may have been distressing or may have provoked difficult emotions for participants. The potential need for extra support was acknowledged in the participant information sheet and carefully monitored throughout the process.

2.4 Procedure

2.4.1 Informed Consent

2.4.1.1 Participant information sheets

The information sheets developed for potential participants described the rationale and procedure of the study. They highlighted the fact that participation was entirely voluntary, that participants were free to withdraw at any time without having to give a reason, and that their choice whether to participate or not would not affect their care. The information sheets also described the methods of data recording and storage, and procedures in place to protect their confidentiality. Additional information was provided for participants to ensure that they were aware of the process of review and supervision of the study, and NHS complaint procedures.

2.4.1.2 Consent forms

Separate consent forms were produced for each individual participant to complete, and were designed for patients, partners and professionals. The forms asked participants to confirm that they had read and understood the information provided about the study, and had the opportunity to receive answers to any questions they had. The form ensured that participants consented to the audio recording of their interview, and that they were aware all data would be stored securely, anonymised

and deleted following completion of the study. Participants were asked to initial each point, and to sign and date the form to evidence their consent. Interviews were arranged for at least one week following receipt of consent forms, to enable full consideration of their participation.

2.4.2 Semi-structured Interview Schedules

The interview schedules were developed from a collection of themes emerging from a brief literature review. According to IPA methodology, detailed literature reviews should not be conducted before the analysis is undertaken (Willig, 2008). Therefore, the knowledge and interest in the topic area also added to the development of the schedule, through discussion with the clinical supervisor and staff at the clinic. Identified themes were then developed into sub-themes from which the interview schedule emerged.

The schedules were intended as a guide to the researcher, but to be used somewhat flexibly (Smith & Osborne, 2003). Questions were kept open-ended which allowed respondents to answer in their own way. However, the general structure ensured that the interview remained focused. Participants were given opportunities to reflect with the researcher about the interview process throughout, and to ask any questions. The researcher also checked that the participants understood the questions where necessary.

Separate schedules were prepared for couples and for professional participants. The interview schedules can be found at Appendices 12 and 13.

2.4.3 Data handling, storage and coding

All signed consent forms were stored securely. Data collected were digitally recorded, and the digital files saved on to a secure NHS computer. All data were transcribed by the researcher. Transcriptions were coded using pseudonyms and numbers, to ensure that individuals could not be directly identified.

2.4.4 Interview Procedure

At the scheduled interviews, the purpose of the study was explained again, as well as the participants' role. Consent forms were checked and the implications reiterated. Particular care was taken to re-establish the informed consent of sufferers, given the potential for a change in their capacity, and that they may have changed their minds about participating. Issues of confidentiality and data protection were revisited. Participants were given the opportunity to ask any questions. It was also explained to all participants that they were still able to withdraw from the study at any point. During the interviews, the researcher's role was to facilitate and guide the conversation (Smith & Osborn, 2003). The researcher was familiar with the interview schedule, using it as a guide to keep the interview focused on the topic areas.

At the conclusion of the interviews, participants were thanked, given another opportunity to comment or ask further questions, and offered a summary of the final results after completion of the study. Following the interviews, a brief letter was sent to thank them for their participation.

2.5 Participants

Participants were recruited through the clinic. Potential participants were identified (on the basis of the inclusion and exclusion criteria) through the service database and at routine follow up appointments.

2.5.1 Participant Inclusion and Exclusion Criteria

In determining the inclusion and exclusion criteria, there were several considerations. Firstly, in order to ensure that recruitment for the study was viable, initial discussions were conducted with senior staff at the clinic. Discussions were also held with the Clinical and Academic supervisors of the study, and with other staff members at the clinic.

At the time of the study, the structure of services and diagnostic criteria meant that those aged over 65 were considered to be 'older adults', whilst those under the age of 65 were considered to be 'working age adults'. At this time, different services exist

dependent on the patient's age. Therefore, an upper age limit of 65 for the sufferers was felt to be appropriate.

When using IPA methodology, it is recommended that a homogeneous sample is used, in order that the research question is directly relevant to the particular group of participants (Smith & Osborn, 2003). It is recognised, however, that this homogeneity is affected by the size of the sample, and the success of the recruitment. In this regard, limiting of the sample by overly restrictive criteria would have risked a dearth of eligible participants.

Consideration of these aspects led to the following criteria.

2.5.1.1 Couples

- Participants should be individuals who have been diagnosed with a dementia whilst under the age of 65, together with their partners. Potential participants would be approached if they had received a diagnosis at least 6 months previously.
- No other specific inclusion criteria were set, however there were a number of exclusion criteria.

Exclusion Criteria

- Participants were excluded from the study where it was felt that they might lack the capacity to consent to the process or to decline to participate (according to the stated procedure for assessing capacity) (Department of Constitutional Affairs, 2007)
- Single individuals, or those whose partners did not want to participate in this study, were not able to participate. Although it was recognised that this might limit the sample, it was felt that the focus on couples should be adhered to.
- Potential participants suffering from severe co-morbid mental health issues or recently diagnosed serious health problems were excluded. It was felt that such issues could impact on participants' ability to focus on the research questions, thereby adding complexity to the data.

- If the clinic felt that any potential participant might find the interview process unduly distressing, they did not invite the couple to participate in this study.
- If the researcher had felt at the time of interview that participants were unduly distressed, the interview would be stopped and further advice and support sought.

2.5.1.2 Professionals

Criteria for inviting professional participants did not specify particular people, but broadly included any clinical health professionals who have been involved in the process of diagnosis or support of a younger person with a dementia. There were no specific exclusion criteria for this group, however if the researcher felt at any stage that it would be inappropriate or harmful for them to participate, advice from the Clinical Supervisor would have been sought.

2.5.2 Recruitment

The initial identification of potential participants, and the provision of information packs, was carried out through the clinic, rather than through the researcher directly. This procedure was undertaken in order to protect the anonymity of potential participants and to ensure that people were not consenting due to any perceived pressure or uncertainty about the study.

Potential participants who met the inclusion and exclusion criteria were informed of the study by staff at the clinic, and asked if they might be interested in participating. If they gave a positive response to this, they were given an information pack containing the introductory letter (Appendices 14 and 15), reply slips (Appendices 16 and 17), and information sheet. Potential participants were then required to return the reply slips in a stamped addressed envelope to the researcher, with their contact details. On receipt of these slips, the researcher made telephone contact. For those who then consented to participate, a written consent form for each participant was sent to their home address. Participants were advised to complete it and were told that the researcher would collect it at interview. Interviews were scheduled for between one and two weeks following their receipt of the consent form, to allow for

participants to thoroughly consider their involvement and to give them the opportunity to withdraw if they so wished.

Of the couples participating, one chose to contact the researcher by telephone, and five returned the paper reply slip in the stamped addressed envelope provided. All professionals chose to contact the researcher via email in the first instance.

The researcher then made telephone contact with participants, and email responses to professionals, to clarify their interest and to provide any further information that they wanted. During the initial exchange, the researcher outlined the aims of the study. The participants were asked to partake in a one-off interview together, lasting about an hour, relating to their experiences of coping with dementia and their support needs in this regard.

Couple participants were offered the option of meeting at the clinic base, or of the researcher travelling to their homes. Five couples chose to be interviewed at their homes, and one couple chose to be interviewed at the clinic base. Professionals were offered the option of meeting at another clinical base if preferred, such as a community team base. Two professionals chose to be interviewed at the clinic base, and four chose to be interviewed at a separate clinical base.

Participants were asked to confirm that they would like to take part by way of signing the written consent form. Following the initial exchange, this was sent to them and they were asked to bring it to the interview. The form recorded their consent for the interview to be audio recorded and for direct quotes to be used in reporting the results. It was explained that the interview recording would be destroyed following the completion of the study, and that no identifiable information would be transcribed, to ensure confidentiality.

Couple participants were verbally reminded of the necessity for the researcher to contact their GP's, and details of their GP's were requested. The researcher then prepared and sent the letter and participant information sheet to the GP's of the patient and the partner, separately.

Recruitment continued until the researcher had successfully enlisted a sufficient number of participants.

2.5.3 Sampling

The sample size was limited by the number consenting to participate within the time frame of the study. However, the majority of research using IPA methodology has been conducted using a small sample size – five or six has been suggested as an adequate figure (Smith & Osborn, 2003). This ensures that there is sufficient data to examine similarities and differences between participants, without an excessive amount of data that would overwhelm the researcher. In addition, it is recommended that qualitative data collection should cease at a point where the researcher feels that understanding has been achieved (Elliott *et al.* 1999; Guest *et al.* 2006).

Due to the small number of willing and able participants at the time of the study, it was not possible to enter into strategies of purposive sampling. Purposive sampling is a systematic strategy of selecting participants according to the criteria of the research questions. It was also not possible to address sampling issues in terms of seeking a gender balance between participants. These issues are discussed further as part of the critical appraisal of this study in Chapter 4.

2.5.4 Response Rate

The response rate is unknown, as the researcher was not aware of how many participants were approached but did not wish to take part. Staff at the clinic reported that many of those approached expressed interest verbally but then chose not to make contact with the researcher. Further reminders were provided by the clinic, with the understanding that the busy nature of their lives and the effect of having a cognitive impairment may make it more difficult for potential couple participants to take the initiative in contacting the researcher.

Professionals were approached via the clinic, and by the Clinical Supervisor of the study. As far as the researcher was aware, only one professional expressed verbal interest but did not subsequently participate, and none declined to participate.

All participated fully, thereby being appropriate for analysis.

2.5.5 Description of Participants

The study included six couples, and six professionals. This section presents a description of each participant. Names and identifiable information have been changed throughout the study, in order to protect their anonymity.

Couples

Anthony and Alison

Anthony was 61 years of age, and Alison 59. They had been married for 37 years, and lived together with their son and daughter. Anthony had begun to show symptoms of a possible dementia 4-5 years previously, and after a long and complex assessment process, it was thought that he might have Alzheimer's disease and he was prescribed anti-dementia medication. The diagnosis had more recently changed to frontotemporal dementia, and the medication was stopped. Anthony had run his own business and Alison had worked full time, but both had stopped working soon after Anthony's diagnosis. They had not had the opportunity to attend a support group initially, but had later become very involved in setting up and maintaining peer support groups.

Brenda and Brian

Brenda and Brian were both 62 years old and had been married for 39 years. They had a daughter, a son who had died a few years previously, and 5 grandchildren of whom three lived locally. Brenda had a diagnosis of probable young onset Alzheimer's disease, with symptoms first noticed 2-3 years previously, and had taken anti-dementia medication since diagnosis. The couple had chosen not to attend support groups, but Brenda had individual support sessions. Brenda had worked part time until just prior to diagnosis, and Brian was still self-employed.

Connie and Colin

Connie was 58 years old, and Colin 67. They had been a couple for 10 years but were not married. Connie had been widowed a year before meeting Colin. Each had two children from their previous relationships. Connie had a diagnosis of probable young onset Alzheimer's disease and was taking anti-dementia medication. The couple attended support groups occasionally and had sought support from the

Alzheimer's society. Connie had worked in a professional capacity until a few years previously.

Diana and David

Diana was 61 years of age, and David 62. They had been married for 38 years, and had two adult daughters, one living nearby and the other living elsewhere in the country. Both had worked in professional careers but had retired some years ago, due to Diana's poor physical health and increasing cognitive difficulties. Diana had had a diagnosis of young onset Alzheimer's disease 2-3 years previously and had taken anti-dementia medication since diagnosis. The couple had been heavily involved in setting up local peer support groups, and continued to strongly advocate for these and for younger people's services.

Elaine and Eddie

Elaine was 57 years old, and Eddie 59. They had been married for 34 years, with two sons and three young grandchildren. Elaine had had a diagnosis of early onset Alzheimer's disease around 2 years previously, and had been taking anti-dementia medication since being diagnosed. Both had worked all their lives in semi-skilled professions, and they had both given up work around the time of the diagnosis. They had attended some peer support group meetings at the Alzheimer's Society.

Frankie and Felicity

Frankie was 64 years old, and Felicity was 62. They had been married for 40 years, had a son and a daughter, and 5 grandchildren of ages ranging from pre-school to teenage. The couple had recently moved house and now lived near their daughter and her family. Frankie had had a probable diagnosis of young onset Alzheimer's disease 10 years previously and had been taking anti-dementia medication since diagnosis. Frankie had worked in a skilled job all his adult life, and had finished work on the grounds of ill health after receiving the diagnosis. The couple had not attended any support groups, though Frankie had undertaken individual therapy.

Professionals

Gareth had a background in Adult Mental Health. He was in his forties and had been working with younger people with dementia for 4 months at the time of interview.

Heather was in her thirties and had worked in older people's mental health and dementia care services for several years, with both older and younger people.

Ian was 50 years old, and had worked in older people's mental health services for 26 years. He had begun working with younger people with dementia about a year previously.

Jane was in her late fifties and had worked in Older Adults services for over 30 years. She now worked with younger people with dementia and had done so for about a year.

Keith was in his fifties and had been working with younger people with dementia for 8 months. He had worked for 5 years with older adults with dementia in a community setting.

Leanne was in her twenties and had been working with younger people with dementia for 8 months. She had not had prior experience of working with people with dementia.

2.5.6 Interview procedures

The interviews were arranged at convenient times and locations for the participants. A single interview was carried out with each couple together, and with each professional individually. At the beginning of each interview, participants were reminded about the background to and nature of the study, and of their right to withdraw at any point. Participants were asked if they had read and understood the information sheet and whether they had any queries about the study that they would like addressed. Finally, participants were asked to sign the consent form.

All interviews were recorded using a digital audio device. The couples interviews varied in duration from 55 minutes to 120 minutes, and the professionals interviews ranged from 42 minutes to 65 minutes. After the interviews, participants were given an opportunity to discuss the interview. Considerations had been put in place in the event of participants becoming distressed or requiring further support, however this did not arise.

2.6 Data analysis

The audio recordings of each interview were transcribed verbatim. The typed transcriptions were studied in detail by the researcher, and the procedure for IPA analysis was followed as described below.

Guidelines for the analysis of data using IPA involve a number of stages (Smith & Osborn, 2003; Willig, 2008). At the first stage, the researcher reads the transcript numerous times, identifying themes, ideas or points of interest. The second stage involves the interpretation of these points, and labelling of themes, with the aim of capturing the essence of the points of interest using the participants' descriptive language. Thirdly, these emergent themes are structured more coherently, examined for relationships and clustered into groups accordingly. This generates 'master themes'. This procedure is then repeated for all cases, before integrating all the study data according to the previous stages. Master themes can be used to guide subsequent analysis, though this does not preclude their expansion to add new themes, or to the discarding of some themes if they are not relevant to other participants. Finally, the master themes are summarised with their groups of subordinate themes (Willig, 2008). The finished analysis should provide a summary of the essence of the phenomenon under study (Willig, 2008), and of the nature and quality of the participants' shared experiences. The primary themes were highlighted at the completion of each interview analysis, and any new themes identified were then incorporated. The researcher followed this process with all transcripts, to arrive at a number of superordinate themes and master themes. These are presented in Chapter 3.

Examples of the data analysis procedure can be found at Appendix 18.

2.7 Dissemination of results

Participants were all offered the opportunity to receive a brief written summary of the study following its completion. All participants stated that they would like to receive this, and the researcher agreed to provide a summary sheet following completion of the study. This would outline the study's main findings and a synopsis of the clinical and service implications. It is anticipated that an account of the study will be written, along with the academic and clinical supervisors, to be submitted for publication in relevant journals. Additionally, the researcher offered to present the findings from the study to interested services.

CHAPTER THREE: RESULTS

3.1 Overview

This chapter will outline the main themes that emerged from the data gathered within this study. In accordance with the approach suggested within IPA methodology, once the researcher had become familiar with each individual interview, all areas of specific interest within the transcripts were noted, leading to the development of a list of emergent themes. These themes, which emerged from the analysis of all of the interviews, will be presented. The superordinate themes and the master themes will be defined, and direct quotations from the transcripts will be used to illustrate these definitions. The relationship between themes will also be explored. Couples' results and professionals' results will be presented separately (in Sections 3.2 and 3.4 respectively) and summarised together at Section 3.6. A complete table of themes can be found at Appendix 19.

For clarity, participant groups will be referred to throughout this chapter as 'sufferer' to refer to the person who has a dementia, 'partner' to refer to their spouse, and 'professional' to refer to a staff participant. When referring to both sufferer and partner together, the term 'couple' will be used. 'Participants' will be used as a collective term to refer to the group of couples.

Couples provided information to the researcher about the details of treatment they received during the process of diagnosis, and about their family situation. This information was considered to be contextual, and although it may affect the emergent themes in this chapter, such information was not analysed specifically as separate themes.

Likewise, the professionals provided background information to the researcher about their specific role in response to questioning. This was intended to develop rapport and to give the researcher an idea of the level of their involvement and types of issues they face in their work with younger people with dementia. Again, this information was not analysed as emergent themes but was used as contextual information.

3.2 Results - Couples

Overview of themes from couples

The primary emergent themes that were developed through the analysis of the couples interviews are presented in Table 3.

Table 3: Superordinate and Master Themes - Couples

Superordinate Themes	Master Themes
View of dementia	Early symptoms “There’s something wrong” Finding alternative explanations Model of dementia
Living with a diagnosis	Diversity of emotions Unpredictable lifestyle
Effect on couple relationship	Change in roles Couple identity Control and responsibility
Relationships with others	Lack of awareness Isolation
Coping strategies	Social identity Practical strategies Emotional strategies
Reflections on treatment and services	Uncertainty Need for increased awareness Timeliness of post diagnosis support

Each of the themes in Table 3.1 will be described, using quotations from the transcripts to illustrate them. Quotations will be presented either individually, or as an exchange between the couple. For each quotation, the location within the transcripts will appear in brackets as name of participant, [S] to indicate that the quotation is by a sufferer or [P] to indicate that the quotation is by a partner, and the page number within the transcript.

3.2.1 Theme 1: View of dementia

Early symptoms

“There’s something wrong”

Finding alternative explanations

Model of dementia

All participants discussed the significance of feelings experienced since early in the course of the dementia, and their views of these in hindsight.

3.2.1.1 Early symptoms

Some participants felt that they were now able to look back and recognise that some minor difficulties, which were at the time perceived as somewhat unusual or strange, may have signalled the appearance of dementia symptoms:

“Anthony [S] always had the patience, suddenly it was stick a nail in there, we’ve got a cable running in the kitchen, he just tapped a nail in there rested it on the top. We thought “oh my goodness”. He put some shelving in his wardrobe, it was dire, we just thought he couldn’t be bothered. Looking back now there was something going on, we all feel really badly we didn’t know or understand what was going on, he obviously didn’t know either ... in hindsight when I talk to people, this is the saddest bit, because he had always been a hard worker, and perfectionist with the work he was doing. They also noticed “that’ll do” work wise, but nobody ever thought to phone me and say “I think he’s struggling”” (Alison [P], P.8)

For one couple, there was a feeling that others were concerned but without a clear sense of why the sufferer was not coping as well as previously:

[S]: I gave up work because I was not feeling very well, ... in the end I decided, well they told me, you’re tired, it’s enough, and it’s better to retire. I didn’t want to retire.

[P]: So [Diana] retired I think in 1999, just before 2000, I was still working but then we noticed she started getting quite anxious cause she had to stay on her own” (Diana and David, p.4)

3.2.1.2 “There’s something wrong”

Continuing this theme, half of the sufferers expressed awareness of a serious change in themselves, but were unable to articulate this at the time:

“I knew there was something wrong, I knew” (Connie [S], p.6)

“See that ‘A’ word [Alzheimer’s] how I look at it (long pause) it is weird, I knew I had something wrong with me” (Elaine [S], p.2)

One sufferer described this as concern for her partner as well as for herself:

“I didn’t want to worry [David] you see and I didn’t know what was going on. In the end I had to tell him, because the way my head was feeling and the way I was feeling I really didn’t feel safe ... I felt quite down and I don’t go down, basically because I felt very much hemmed in the house. When I think about it, I think of darkness, I wasn’t happy in myself. Basically I knew something was wrong” (Diana [S], p.17)

3.2.1.3 Finding alternative explanations

Most participants discussed the personal meaning that these early symptoms had for them, and the sense they tried to make of them at the time. Early symptoms tended to be explained away by putting them down to other factors. For example, symptoms were thought to be due to stress about family circumstances:

“Going in a shop to buy something and coming home with nothing... [Eddie] thought it was stress because I was looking after my uncle. After [my uncle] died I put it down to the buzz has gone and stress ... I was sorting that out, sorting my grandkids out, and I thought “no you are doing too much”, but I wasn’t taking any notice of what [Eddie] said. I knew in my heart it was wrong ... it was like [Eddie] watching the news or something and he’s having a conversation, and I wanted to scream at him because I didn’t know what he was saying” (Elaine [S], p.8)

Other participants considered symptoms to be caused by stress at work:

“[After having difficulties at work] From then on [Brenda] was on the sick for several years with anxiety, I don’t know if they call it anxiety, depression, I’m not sure. I think that was the start of the memory problems coming in. Yeah that’s where it all started” (Brian [P], p.4)

And

“Mine was stress related from being bullied [by a colleague]... it was awful, it just gave me a nervous breakdown” (Connie [S], p.3)

Other participants described presumptions about the early symptoms being related to problems with the sufferers’ physical health:

“They [friends/work colleagues] thought it was the knee, they felt sorry for him because his knee was bad and in some cases some of them would help you, they’d help him” (Alison [P], P.8)

One sufferer described some possible factors that she thought had contributed to the causes of her dementia:

“Because I do use my brain ... I stopped using it, I think maybe that’s when I was doing the damage more, because I didn’t use it. And then I took ill, I have had that many operations it’s unbelievable. And it makes you wonder, ‘cause in one of the operations I stopped breathing, something happened to me, they were worried and panicking, I think they thought they’d lost me” (Diana [S], p.10)

Some partners also reflected on potential causes of the dementia for the sufferer:

“It could be lifestyles, it could be everything but [Elaine]’s medical condition, I think it’s a lot of medical conditions. [Speaks to Elaine] how old was you when you had the hysterectomy? (pause) you were only young, 27 ... so straight away she is not getting any oestrogen ... I think all them things all add up to these conditions” (Eddie [P], p.21)

3.2.1.4 Model of dementia

Most of the participants expressed a presumption about dementia only being applicable to, and experienced by, older people:

“I think younger people also see Alzheimer’s as dementia as an older thing, I don’t think it’s ... recognised as being prevalent in younger people as well” (Colin [P], p.22)

“[S] [Eddie] couldn’t grasp it and I thought “I know it’s there”, I couldn’t grasp [the diagnosis] I couldn’t believe it and I got very angry. I think, because you are so, you know, fifty six when they told me, and I thinks to myself “well if I was sixty eight (pause) or seventy I could grasp it a bit better”.

[P]: You expect to see things like that in older people” (Elaine and Eddie, p.2)

The participants’ personal views about dementia were fundamental to their expectations and feelings about their own experiences of it. Some frustration and sadness was expressed when discussing their early symptoms, which had not been attributed to dementia at the time of occurrence.

3.2.2 Theme 2: Living with a diagnosis

Diversity of Emotions	Fear of the future Feeling of being stigmatised
Unpredictable lifestyle	Dealing with uncertainty Holding on to hope Loss of activities

3.2.2.1 Diversity of Emotions

A range of themes were related to 'Living with a diagnosis', centring on emotional responses and concerns.

Fear of the future

Some of the sufferers expressed difficulty in accepting the diagnosis, and spoke about a strong fear of what this might mean for them:

"When the initial [diagnosis] came I couldn't grasp it. It's hard because I am a very independent - I was a very independent person and I don't want nobody taking my independence from me. This is what I can't adjust to" (Elaine [S], p.5)

Half of the sufferers reported that one of their parents had had dementia, but only one felt that this had affected their subsequent view of, and fear about, their own symptoms:

"I think I'm frightened I'm going to end up a vegetable, you know, like my mother. She couldn't talk or anything, she just sat there" (Anthony [S], P.15)

Most participants felt that they had gained more knowledge about dementia since the diagnosis, through peer support groups and through personal experience, but that this knowledge has engendered fear and worries about what will happen over the course of the illness:

"[Brenda] was a bit upset at a couple of the people there [at a support group], how bad they were. There was one lady, she had a comfort blanket type of thing, things like that" (Brian [P], p.16)

And

"I have worked with people who've got [dementia] and um it's not nice, it's like my best friend, her mum is in hospital, and um its dementia, I walked in there to see her and we had a laugh but I can't go back in there because being honest when I am in there I am looking and I am thinking am I gonna be like you? It's not a nice feeling" (Elaine [S], p.10)

One couple talked about the portrayal of dementia in the media, and that watching such portrayals can be distressing for them in reflecting their own fears:

"We know (sigh, pause) we know it's going to get worse. But you've got to take each thing as it comes. And it's got to be upsetting when there's people on the television and they're saying about, you know, things in Coronation Street, there's a lady in Coronation Street got it [dementia] and she couldn't remember her husband's name ... I'm thinking, will a time come when he won't remember me?" (Felicity [P], p.18)

Sadness was also expressed with regard to the loss of the future that the couples had expected prior to diagnosis:

“[P]: The young people, when you’ve got it [dementia] like because we’re so young...”

[S]: And you’ve still got plans in your head

[P]: Plans that you might never have completed but the option was there”

(Elaine and Eddie, p.1)

Feeling of being stigmatised

Most participants felt that there was a societal stigma attached to a diagnosis of dementia. This was expressed particularly around the view of dementia being a part of getting old, and therefore not being expected by a younger person, but also in terms of the participants’ experiences of the reactions of those around them:

“It’s as if it’s a disease you can catch. That’s how I look at it, that’s how I think people do, I don’t see any of my family so much now, do I?” (Anthony [S], p.25)

And

“It’s the word “Alzheimer’s”, because there is a stigma to it ... for old people, you say “Alzheimer’s” and people think you are gonna be sat in the corner ripping paper or dribbling from the mouth ... it makes you feel terrible, and for a young person to have it... The way people perceive Alzheimer’s – “aw you’re thick” or “is she gonna be weeing herself” and it doesn’t happen that way” (Elaine [S], p.10)

Participants felt that they had experienced a loss of past self / identity, and this led them to feel vulnerable and overwhelmed:

“It’s not me. It’s not me to not be able to read a book, to read a book on holiday, to blooming read a newspaper ... I still try with a book, but I am being perfectly honest with you, I read the Kindle and I don’t know what I am reading, but I am still persevering because of [Eddie] and my boys. Sometimes I just want to throw it all down and say “sod it” “ (Elaine [P], p.36)

3.2.2.2 Unpredictable lifestyle

The inability to accurately make predictions and plans about the future meant that to participants had to continually adjust their expectations of the future, and live with the unknown.

Dealing with uncertainty

The often inexact nature of dementia diagnosis and treatment was very difficult for most participants to cope with:

“That’s the most difficult thing, because you want answers. I didn’t understand at the beginning, now I understand when they said how is it going to be, is it going to be like this this and this, we can’t say, we don’t know ... But because there isn’t a definite diagnosis, I’d almost feel a sense of failing if it then works out “well, actually, he did have Alzheimer’s and by having medication it could have made him better for longer”. That’s something I struggle with but we’ll never know. It’s a progressive thing, so just wait and see” (Alison [P], p.16)

And

“So far, we don’t know what the future’s going to hold, what happens” (Brian [P], p.9)

One sufferer used the analogy of a cancer diagnosis to describe how difficult their dementia diagnosis felt:

“it was just a black hole I could have literally been swallowed up and taken, ‘cause it was an awful word to use ... if you told us we had the “C” word (pause) we would have coped with that better than the “A” word because with the “A” word nobody knows what’s going to happen to you ... The uncertainty is the hardest thing” (Elaine [S], p.33)

However, some participants did make acknowledgement of the reality of the diagnosis:

“I shouldn’t be doing it at my age ... I shouldn’t be doing all this and sat thinking to myself well, (pause) you know next year, if I live, if I stayed like this for 10 years I would be over the moon. In reality, it’s common sense, nobody stays like that when you have been diagnosed with Alzheimer’s. You are very stupid if you believe you’re gonna be like this in 10 years, you are very stupid and very naïve to believe it. You know you will deteriorate, it’s common sense (pause) you know that is what the disease is” (Elaine [S], p.39)

One sufferer felt that she was maintaining a sense of control over the uncertain future by planning an advance directive:

“I do not want to be sat in that chair and not recognise my children. I do not want to be around, whether it’s 3 years’ time and I am only 60, whether its next year ... the day I can’t see my children, I don’t want to be here. I know that’s cruel and hard for [Eddie] to understand ... for my own dignity, I have always said to [Eddie], I want to die, promise me?” (Elaine [S], p.35)

Holding on to hope

Some participants were dealing with the ambiguity of an uncertain diagnosis by retaining optimism that the medical professionals might be incorrect about the sufferers having dementia:

“I told all of his family, we treated it as such good news, “its not dementia”, whatever’s happened’s happened, they have nothing to tell us why, but it’s going to be a long time before things get worse” (Alison [P], p.15)

And

“He [the doctor] spoke to me first cause [Diana] was in another room, and he said 80% certain it is Alzheimer’s ... ‘cause it was always a percentage, there isn’t an actual” (David [P], p.15)

And

“I knew my doctors, how good they are, and it was a new doctor. I went to see him ... he said to me “I am so sorry, you are very young to have Alzheimer’s, the youngest in the surgery”. And I looked, I said “show me the screen, how can they tell me I got Alzheimer’s when my scans are coming back not yellow or blue or whatever”?” (Elaine [S], p.56)

Loss of activities

Most sufferers reported that they had drastically cut down the amount and type of activities that they engaged in, and tended to stay at home much more:

“I was always out every day, out looking after my mum, looking after my aunties, working, looking after the grandkids, now I don’t want to even get dressed in the mornings. I am just in here, I go out once a week ... It is a big shift for me” (Elaine [S], p.5)

This was also the case for some partners:

“I’ve stopped going up the pub as much as I used to. I used to go up the pub every Tuesday, on a quiz night with some friends, I’ve stopped doing that. I’m not really sure whether that’s so much to do with [Brenda], or I just got fed up of going - whether it’s connected I’m not really sure. But I’m quite happy to come home in the evenings, just watch the telly, have a glass of wine” (Brian [P], p.13)

A diagnosis, and the ongoing symptoms, of dementia have a unique impact on the sufferer and partner. Some key elements of the type of impact are reflected within this theme, such as emotional changes and lifestyle changes. For the younger people in this study, the uncertainty and stigma seemed to have a profound effect.

3.2.3 Theme 3: Effect on couple relationship

Change in roles

Couple identity

Control and responsibility

3.2.3.1 Change in roles

The main impact on the relationship between sufferer and partner came from a forced shift in responsibilities, where partners took over more responsibility and everyday tasks previously carried out by the sufferer:

“Suddenly our roles had changed, and that’s the one thing I really struggle with, is when I need work done and I don’t know how to get it done, you know, how to organise people to do it that I can trust. So [Anthony] would just take care of it, he always knew somebody who knew somebody” (Alison [P], p.22)

The change in roles also meant more of a shift towards a ‘carer’ role by the partner:

“Yeah I think there’s obviously a care element to my role now. It’s always been there, you know, we care for each other normally. But it’s grown a little bit since the diagnosis, and sometimes that’s difficult” (David [P], p.29)

Most partners felt that they had adjusted to this over time and were happy with the change in roles. However, one partner said that he still resisted the shift towards a ‘carer’ role:

“I’ve never classed myself as a carer, I haven’t got a lot of patience” (Brian [P], p.9)

3.2.3.2 Couple identity

The changes in roles led to fluctuations in the couples’ sense of shared identity:

“The effect [of the dementia] is huge, absolutely massive. We are a very, very old fashioned couple, extremely. [Anthony] did all the jobs, he did the repairs, took out the rubbish, he organised any building work that had to be done, he did everything. I did the shopping” (Alison, p.21)

For some, the couple relationship seemed to be somewhat strengthened. Some couples expressed that their communication had actually improved:

[P] It must be very hard, very difficult, but with two people involved I think the important things we’ve always talked about.

[S] And we always talk. If I don’t like something, I tell him and he tells me, and we talk about it.

[P] You fall out over the little things, but the important things ...

[S] ... You stick

[P] You stick, yeah” (Diana and David, p.16)

3.2.3.3 Control and responsibility

Participants described fluctuating patterns of the partner taking more control over their daily lives, and the sufferer relinquishing control over some aspects:

“I compensate now, yeah I do all the cooking now. [Brenda] doesn’t do any cooking anymore. I just gradually started doing it, because she just lost confidence, how to time things and do a cooked dinner. She used to be able

to do everything and do all the cooked dinner exactly the same time. She would start doing something, but forget to do the potatoes or the carrots or that type of thing, so I tend to do all the cooking now. If I'm not here she usually has a sandwich or something. But she doesn't use the cooker" (Brian [P], p.10)

And

"[S]: At the end of the day, it seems that slowly, slowly, everything is taken from me. I just do not like it, you know, it's like my life is taken from me. I am very lucky. I am in a stable marriage, I've got good children, I've got [Eddie]. In fact, sometimes he is too overbearing ... it's not that he wants to control me ...

[P]: I wouldn't know where to start (laughs)

[S]: No, but he is concerned about me and I say "no, you just leave go, just let me do my own thing". They don't mean to do it, they try to smother you and try to take control, and there is no need to take control ...

[P]: ... It's all a control thing isn't it, your fear of losing control.

[S]: Yeah, that's what it is, it's fear of losing control at an early age" (Elaine and Eddie, p.15)

One partner described a strategy for helping her to feel more in control of their situation:

"As long as I had my list, it was almost as if "right, I can do this, I can get this done". If I looked at the whole picture, I think I'd have cracked up completely and utterly. If I can tick one box get one thing done" (Alison [P], p.19)

However, the continuous struggle for control led to increased frustration and worry for some sufferers:

"It's the anger, so much anger in me. I'm not volatile but I am getting so nasty towards people. I go to the Doctor's and I see all these young kids on drugs ... I think, I've got a loving family and everything, then why have I got this [dementia]? Yeah, it's really, really unfair and I haven't got a daughter (pause) and I cannot expect my boys to look after me (long pause) you know, to wash me, it's too much. He [Eddie]'s doing silly things now, but I think he is under stress because of me" (Elaine [S], p.18)

A major part of the struggle for control involved the partner increasing their monitoring of the sufferer, predicting that they will forget things or make mistakes:

"I try to keep spare cigarettes in the car cause she often forgets she hasn't got any and she'll say "I've got no cigarettes", so I've always got some in the car" (Brian [P], p.13)

From the increased 'taking over' resulted feelings of being overprotected by the partner. Resistance to this caused increased frustration and anxiety in sufferers:

[S]: It is the stress with [Eddie], he means well but I keep on saying to him, "it's not me with Alzheimer's, you got the Alzheimer's"! I know it's stress, if I go out with my aunts or something. Like the other week, I was an hour late and he was panicking. I should have phoned the house but I am not useless, I am not used to phoning ...

[P]: I wouldn't say I was panicking, I check up on you, I've gotta be concerned haven't I. There could come a time when you go out on your own, where you get a bit panicky. But, if I am not with you when you are on your own, I have got to panic, I mean if you break down or got a problem, if you don't ring me then I don't know, do I?

[S]: He means well, but I've gotta do it for myself, I've gotta do it. If I make mistakes, I make mistakes"

(Elaine and Eddie, p.18)

However, not all sufferers felt that the increased monitoring had negative effects, but could actually help them to feel safer:

"I do sense, because [family] feel they have to look after me a little bit more than they did before, when I go out I am a bit more conscious because they're watching to make sure that you're safe. That's what I feel, and I'm glad of that because, you know, if I'm not very well, having a bad day then I could walk away couldn't I?" (Diana [S], p.28)

The changes in the relationship between the couple were described as centring on the balance of control, with the partner wishing to help and protect the sufferer, and the sufferer's distress at their loss of abilities. Most couples in this study felt they had had traditional gender roles within the relationship previously, which were now being challenged by the effects of the dementia.

3.2.4 Theme 4: Relationships with others

Lack of awareness

Isolation

Participants reported that the diagnosis changed their relationships with family and friends.

3.2.4.1 Lack of awareness

Most participants felt that other people did not understand dementia, and sometimes that others did not or could not accept that a younger person could have dementia:

[S] Because I act normal, I'm not showing any signs of it [dementia], I can fool them, they forget sometimes that I have got it. And some people don't understand, sometimes I might make a mistake, and they don't understand why I've made that mistake.

[P] Especially, sometimes, when she tells people she's got Alzheimer's, that's what she reads in their eyes. It's a little bit of a shock because they probably don't expect her to have it, they don't bear it in mind that she's got what she's got.

[S] Yes and sometimes people look at me and think "you ain't got Alzheimer's" and they think I'm lying, you see.

[P] Well, you're talking about that word 'dementia', aren't you, and early onset Alzheimer's is totally different to later onset dementia. As you can see, [Diana] will be in company for a while before something might happen that would tell me 'that's the Alzheimer's there', but others wouldn't recognise it" (Diana and David, p.22)

Some participants felt that since dementia is not a visible condition, it was perhaps easily overlooked in some circumstances:

"How do you know until you really get involved with someone that there's anything wrong with them? Because if 10 people walked into the room now and we all had a cup of tea and a little chat, you could never tell which one was ill" (Frankie [S], p.9)

3.2.4.2 Isolation

Participants reported that friends and family had withdrawn from their lives since the diagnosis. This was acknowledged in exchanges between couples:

[P]: We lost all our contacts. [Anthony] wasn't out there, he was just not aware of all the contacts. Yeah, and family, we've lost family as well.

[S]: I lost a lot of friends when I became ill. People wouldn't want to see me, like your sister lives round the corner, and she don't even come and see me.

[P]: They'd cross the road, 'cause they couldn't deal with it. It is difficult, I think, for them, because we just don't see people. You know, suddenly the doorbell never rings"

(Anthony and Alison, p.23)

And

[S]: I have noticed it with [Eddie's] brother, don't get me wrong I don't think he is shunning me.

[P]: No, they don't know how to handle it.

[S]: Like my children didn't know how to handle it"

(Elaine and Eddie, p.9)

For some participants, the isolation and stigmatisation resulted in increased difficulties in trusting other people:

“Not trusting people no more, that’s new to me. Before, I was too trustworthy (laughing) wasn’t I, but now I draw that barrier” (Elaine [S], p.39)

Some of the couples reported that they had deliberately tried to hide the diagnosis from others, out of fear about what their responses might be:

“I think he [Frankie] would have to be really close to them and bother with them a lot before it would come up. Unless he felt that perhaps they were noticing something wrong, but if he could get away with [hiding] it, I’m sure he would” (Felicity [P], p.13)

And

“We got one grandson, he is 16 in May. He done all his exams, so we kept quiet about it because we had him with us more. Concealing that, we’ve done it quite well haven’t we? How much longer we can I don’t know but ... perhaps we can have a word with him then, but the little ones, apart from the one who is very advanced (laughs), they just carry on as normal, they just say “silly nanny got the wrong names again”” (Eddie [P], p.10)

It was reported that there seemed to be very limited awareness about dementia in the community, particularly about how it can affect younger people. Many participants felt that the expectations and fears of their friends and family had resulted in others avoiding the couple since the diagnosis, resulting in a strong sense of isolation, and feelings of anger and sadness.

3.2.5 Theme 5: Coping strategies

Social identity	Developing compensatory relationships Finding a group identity
Practical strategies	Keeping busy Distraction
Emotional strategies	Building confidence / self esteem Acceptance Positive thinking Avoidance

3.2.5.1 Social Identity

Developing compensatory relationships

Most couples felt that the isolation had in fact led to them making new relationships with people they had met through support groups:

[P]: Everybody has different needs don't they, but it just makes a difference 'cause you know what people are going through. [Another carer] would say "yeah I've cried all day today", and I can think "yeah I understand that" ... So I would take part in as much as I can because that's our future, I see it as the future for us. Because without those people and the activities that we go along to, we would just be very lonely, extremely. People are very busy, they get on with their lives, but they don't really understand dementia and they don't really want to, it's seen as mental illness.

[S]: Try and make a lot of new friends.

[P]: Yes, that's a good point, people who are going through the same thing have some kind of contact. But the biggest thing is that because you're dealing with the brain, no two people are the same, you can't compare. So that's been the biggest learning curve for me"

(Anthony and Alison, p.33)

Finding a group identity

Some participants felt that it had been valuable to them to develop a shared identity with other younger people with dementia, through these compensatory relationships.

For some, it provided a sense of support:

"You help each other, don't you, with this [dementia]" (Connie [S], p.21)

And

"We're together, I'm with people who've got [dementia] and we're all with our people who are looking after us, and everybody has a big old laugh together, clears the air. If people have got problems, you go and speak to [David], or he will ask "does such and such do that" and we talk about it, and it's fantastic. We feel confident, and they go we go and vice versa if we go somewhere and we tell them and we go there don't we. It's lovely, it's like a little community" (Diana [S], p.48)

For others, group identity helped them to somewhat normalise having a young onset dementia:

"The group I go to, that helps us because (pause) we can let our inner feelings out. I mean, there are young people out there, there might be somebody younger than me with Alzheimer's, and it's gonna be hard for them. I don't know the youngest person but there is bound to be somebody younger than me with Alzheimer's" (Elaine [S], p.15)

3.2.5.2 Practical strategies

Most couples discussed strategies that they employed around behaviour and activities to manage the symptoms and emotional fluctuations resulting from the dementia.

Keeping busy

Some sufferers described a personal ethos of the importance of 'doing things', and felt that this served them well as a coping strategy:

"I think it keeps you going because if you sit, mam always told me this, if you sit down and think of things, it goes worse. Stop it, get up and do something, don't sit there and think about things, you're going to make it worse. Do something, get your mind off it. If you can solve the problem solve the problem, if you can't solve the problem, get on with it. No good sitting there feeling sorry for yourself" (Diana [P], p.31)

And

"You've just got to get on, you know ... I'll stop if I have to. I can't wait for it to get better, because I can't sit still long enough. But that's life" (Frankie [S], p.17)

Some partners felt that it was important for them to encourage the sufferer to keep doing stimulating activities:

"We play cards every morning, that's something we've done ever since the diagnosis ... [Diana] loves the cards, I sometimes get a bit fed up of it, but it's really good for her. She plays every morning, and I'm sure that in the mornings it's really good 'cause it wakes her up. I notice when we don't play, she tends to stay on a sort of level that she doesn't actually get herself going" (David [P], p.36)

However, one partner felt that this need to keep busy served a function of diverting her from dealing with her husband's symptoms early on in his illness:

"I think it's an awful thing to admit, it takes a lot to admit it, but I think it was easier for me to go to work than it was to stay home at that stage with [Anthony], because it was like I was keeping everything together. If I can do this and this, and my work, I could just switch off, so when I came home then I had time for him, but I wasn't surrounded by it" (Alison [P], p.21)

Distraction

Some participants discussed the importance of engaging in new activities, or adapting old ones, to stimulate the sufferer:

“[P]: Even if the telly’s on, we don’t have to be watching it, but if there’s something there that takes the attention away, that’s good for Alzheimer’s sufferers. Because if you just sit there you’re going to go inward.”

[S] It’s so important, do you know something, it’s even the light, like now it’s going dark. I have learned just recently that I need the light”

(Diana and David, p.35)

Some partners discussed the importance of distracting the sufferer with different activities, and found this helped to minimise frustration:

“That’s one of the things I notice with [Diana], if she is in what I call one of her dark moods, the thing to do is to get her to do something. Take her out, give her something, just change the environment and the experience she’s having”
(David [P], p.32)

3.2.5.3 Emotional strategies

Participants used a range of strategies to cope with the emotional responses to the diagnosis and changes.

Building confidence / self esteem

Some partners discussed their sense of value of their ‘carer’ roles, in supporting the sufferer:

“Once the confidence goes, I think you’re on a downward spiral, but to give [Diana] confidence, that’s my job really, to keep her confidence up. [Diana] has never been brilliant at crosswords, but she can do, you know she’s pretty good. So if I can help her out doing it, it gives her confidence, and that’s very important. Because with her confidence the way it is, it makes my job easier anyway. I mean I don’t necessarily help her as much as I perhaps could do, part of that is because I’m a lazy b- (laughs) but part of it’s because I want her to have the confidence to carry on doing it” (David [P], p.37)

Acceptance

Some participants felt that they were aware of their tendency towards negative feelings, but this awareness helped them to accept them and move on:

“I get upset, I do get upset but after that then “oh yeah you got to get on with it”. You can’t do anything different, it’s not going to change. You’ve just got to live for today, I’ve learned that. If we want to do something, we do it... if we want to go we just go, we’re lucky we can just do what we want to” (Felicity [P], p.15)

And

“Before, I would fret, I would get upset at silly things (pause) now it just goes over my head. These [brain] cells are here to stay, I can’t afford to lose anymore cells, and that that’s the way I look at it now” (Elaine [S], p.51)

Some used strategies to break down problems and adapted their usual strategies to take account of the sufferer’s difficulties:

“You can get around things. It’s got to be a proper taking stock of what can be done and can’t be done, and you know working within that” (David [P], p.39)

Some participants reported that they tried to remain humorous about situations as far as possible:

“I don’t worry about [repeating myself], I don’t care, they can listen to me as much as they like (laughs). I find it funny sometimes, you’ve got to laugh about it” (Diana [S], p.23)

Positive thinking

Acceptance of the new reality of living with the dementia included, for some couples, strong feelings about the importance of remaining positive as far as possible and acknowledging the fluctuations they would be likely to experience:

“[S]: Don’t be ashamed of what you’ve got, it is an illness, other people have got worse illnesses than us, and we can do something about it. The fact is, we can do things, we can try and do things. Our partners could help us, by doing it with us again and again. There are ways around it, and I think it’s very important.

“[P]: I think you’ve got to be very positive about everything, as soon as you start feeling negative or sorry for yourself or anything like that you know it gets worse

“[S] I would say, we understand that sometimes you do feel negative because of the way you’re feeling that particular day. But it might not be anything to do with Alzheimer’s, other things come in” (Diana and David, p.41)

And

“We cope you know and that’s they say what it’s all about, making the best of what you’ve got” (Frankie [S], p.8)

“Live for today, do what you can today, don’t put it off, you don’t know what’s in front of you” (Felicity [P], p.22)

Avoidance

For some participants, however, it was very difficult to acknowledge emotional reactions, as well as the diagnosis, to themselves or to other people:

[S] I couldn't talk about it for a long time. Not very good now.

[P]: No, he couldn't talk for ages. That's us, we prefer to cope with things on our own. [Frankie] didn't believe for a very long time, not really, and the children didn't know for a very long time. But no, he wouldn't believe, he wouldn't accept it. And we just carried on life, to be honest it didn't change our lives then. We just carried on doing what we were doing"

(Frankie and Felicity, p.24)

And

"Sometimes I wonder whether these things where people talk to you ... people who are delving into your mind, if you like, and getting you to tell them things ... I wonder whether it's better just to cope with it yourself. 'Cause if you keep raking things up all the time, this counselling thing, I often wonder whether it does more harm than good. Whatever tragedy, or whatever they're talking about, you're just bringing it up all the time. Allowing it to settle down, that's my own personal way of doing things" (Brian [P], p.27)

Participants discussed some ways that they had found helped them to cope with the effects of the dementia. Social identity was a very important focus for couples, as was the need for sufferers to feel accepted within their social groups. Most felt that they had developed new and very rewarding friendship groups, which gave them a sense of belonging and community. The role of the partner in encouraging and supporting the sufferer helped some relationships to be strengthened.

3.2.6 Theme 6: Reflections on treatment and services

Uncertainty

Need for increased awareness

Timeliness of post diagnosis support

All participants discussed their personal journeys through diagnosis and treatment, and reflected on their experiences. Although the couples' stories varied considerably, there were some common themes.

3.2.6.1 Uncertainty

A few of the participants felt that although they could not be sure whether treatment was helping the sufferer, they felt obliged to accept whatever was offered. For them, this went some way towards assuaging worries that they hadn't done as much as they could have to help the sufferer:

“We don’t have to go [to the clinic], it’s only a voluntary thing. I tend to go, ‘cause I think if something happens and if [Brenda] suddenly gets worse, they’ll say “ah well, you should have, you didn’t take up the offer to do this and that did you?” ... they might say “well, if you’d have done this, it might not have got worse” (Brian [P], p.28)

Participants felt that, although services were available to help them in the early stages post diagnosis, most did not have experience of seeking help from services and were somewhat confused by the fact that help was available from several different agencies:

“What I find is, I know people are being helpful, but there seem to be too many organisations, like there’s the Alzheimer’s Society, there’s Help the Aged, there’s this. Seems like there’s all these different charities and they talk the talk, but sometimes they don’t actually do anything, you know. You get the feeling there’s a lot of people out there talking about doing things” (Brian [P], p.21)

And

[P]: It’s very difficult to suss out who is with what, I mean X is I presume Alzheimer’s Society, and X we’re not really aware of where he fits into the organisation.

[S]: I thought he was from here. He should make it a bit clearer (laughs)

[P]: It’s all a bit disjointed”

(Connie and Colin, p.23)

3.2.6.2 Need for increased awareness

Some participants expressed a view that although there were now more specialist services for younger people, the prevailing view of dementia and services being for older people may preclude some younger sufferers from seeking support:

“It is never a young person on that brochure or on the television. It’s always somebody in their early seventies or late sixties. While people are not aware that it can happen to young people, young people should be alerted about Alzheimer’s. The impression is, it’s like women (laughs), if you forget things you are on the menopause, yeah it’s a presumption ... I am lucky because I am getting the help I need, but there’s nothing out there for young people” (Elaine [S], p.20)

And

[S]: Some of them are a lot younger than me ... there’s not many of them going there [to younger people’s support groups] though is there”

[P]: No the facilities are there but ... we were the only two people who turned up. So the facilities are there, but a lot of people choose not to mix with

other people perhaps. I think younger people are put off, they think it's all for older people... the ages they tend to be older people"

(Connie and Colin, p.18)

One participant reflected on the need for increased awareness and resources in dementia services:

"They need desperately to show Alzheimer's/Dementia/Vascular Dementia is not just a geriatric thing, it is for young people. They are getting younger and younger every day you know, and people don't realise it might be hereditary ... Everybody else seems to be getting the funding and we're not, and everybody knows old people will have a little bit of dementia, but they should be studying" (Elaine [S], p.32)

3.2.6.3 Timeliness of post diagnosis support

Views were mixed regarding the current structure of support services. For some, the fact that support is generally offered after a period of adjustment meant that they felt confused and abandoned after being given a diagnosis:

[P]: I think it would have been just how are things going, just a check. I think there was a shock that for 6 months you don't see anybody, I remember saying "so what happens now?" They said "go away, have a good Christmas and we'll see you in the New Year".

[S]: "And we'll see you in 6 months".

[P]: Suddenly that's it. And you're telling people this and they're saying "what, and that's it? Nothing else, that's it?" And as you're telling people you realise how strange it seems, any other illness you would have monitoring, but this is 6 month checks between appointments and that's how it is. Now I understand why, but then I didn't"

(Anthony and Alison, p.32)

Some of the participants felt that earlier support would have been much more helpful and reassuring to them:

"I'd done all the things that I needed to do, and it was less stressful than it had been the previous 6 months. So when people got on board was not, for me, the right time. The beginning would have been the better time" (Alison [P], p. 32)

However, others were happy with the way that services were currently set up, and felt that they had received good support from services:

“In a couple of weeks now I will be going to memory clinic ... the care I have had is really outstanding, you know. [Clinic staff] and all of them have been great” (Elaine [S], p.1)

And

“It was handy having her [clinic staff] come out, she only came out after the diagnosis was made, and the fact that she filled all the forms out was very helpful because it’s about a 20 or 30 page document, so that was good yeah. Yeah, that was very helpful actually” (Brian [P], p.21)

Half of the couples reported that they tended to be reluctant to seek help. One couple described this in terms of their preference for receiving minimal support from services:

[P]: But that’s us, you know some people would prefer to go and talk to somebody.

[S]: We’ve not needed any help have we, I don’t think.

[P]: No. It was fine for us, I’m not saying it would be fine for everybody but it was fine for us you know, you all cope in your own ways don’t you”

(Frankie and Felicity, p. 22)

Most couples reported that they were happy with the support they had received. However, for some, the available services were confusing, and some felt they had been left to navigate the services and support by themselves. Some found it difficult to ask for help, which may have inadvertently conveyed to services that they did not want help. Participants reflected on the need for further research and awareness raising of young onset dementia.

3.2.7 Additional themes

Several themes raised by couples formed part of the background discussions but were not the main focus of this study. Therefore, these were not included in the main results analyses but are briefly described below.

- All participants described in detail the early symptoms of memory loss, the point of realisation that something was seriously wrong and the resulting decision to seek medical input. Five of the six couples discussed their subsequent journey to diagnosis. Their descriptions broadly mapped on to Wilson’s (1989) temporal model of family care in dementia (discussed in Chapter One).

- Having to stop driving was reported to be a major factor in loss of activity and confidence, resulting in low mood, for the two male sufferers but was not raised by any of the female sufferers.
- Four of the couples reported that a strong relationship with a sibling or family member was a factor in helping the sufferer to feel positive.
- Half of the couples discussed physical health problems experienced by the sufferer prior to diagnosis; however, only one sufferer felt that this had direct relevance to their dementia diagnosis.
- Four of the couples reported financial worries or difficulties following the sufferer's forced end of working life. The same number also reported other current stresses within the family (such as moving house or family disagreements).
- Half of the sufferers described past experiences of trauma (death of a child, sexual abuse). Only one explicitly linked this to their dementia, feeling that the dementia had reduced their ability to cope with the trauma.

3.3 Summary of results - couples

The couples' views of dementia and the early symptoms provided an insight into the emotional responses and impact of the early stages of dementia in younger people, and subsequent coping strategies. The coping strategies were instrumental in aiding participants to make sense of the involuntary changes, and their resulting increased need for flexibility. The need to consider the different experiences and approaches is important for considering that people will cope with information and experiences in diverse ways.

3.4 Results - Professionals

Overview of themes from professionals

The primary emergent themes that were developed through the analysis of the professionals interviews were as presented in Table 4:

Table 4: Superordinate and Master Themes – Professionals

Superordinate Themes	Master Themes
Coping strategies of sufferers and partners	Utilising uncertainty Emotional strategies Practical strategies
Factors affecting coping by sufferers and partners	Individual factors Relational factors Systemic factors
Contextual factors in working with younger people with dementia	Challenges for professionals Service challenges Supporting coping processes

Each of these themes will be described and illustrated with quotes from the transcripts. The location of the quotations within the transcripts will be indicated by quoting the pseudonym of the participant and the page number within the transcript.

3.4.1 Theme 1: Coping strategies of sufferers and partners

Utilising uncertainty	Holding on to hope Predicting the future
Emotional strategies	Searching for meaning Comparing with others Maintaining identity Holding on to control
Practical strategies	Keeping going Talking to others

3.4.1.1 Utilising uncertainty

Holding on to hope

It was felt that in acknowledging the uncertainty of the diagnosis, sufferers and partners tended to retain optimism:

“People hear what they want to, they’re trying to extract a particular message ... people pick up very quickly on any tentative language or doubt and try and expand it, and say “well, she has been quite stressed recently”, or “It all happened when she changed job”, and “if only we can do something about these issues, maybe it wouldn’t be as bad” ... That’s where the hope lives. “Maybe the professionals are wrong, and if they’re wrong, maybe it’s not as bad as we think”. So it’s made me very conscious of the language that we use” (Gareth, p.7)

And

“I had a carer say “stress and depression seem to be the onset for the illness, now she’s being treated for depression and she’s not so stressed because she’s finished work, will she recover” ” (Ian, p.6)

Predicting the future

Most professionals felt that there was a strong tendency amongst sufferers to find ways to try to predict the future:

“People will try and see down the track as it were by comparing themselves to other people’s experiences” (Gareth, P.10)

However, this tendency was felt to vary widely between individuals:

“Some say “no, I don’t want to know, I don’t want to be surrounded by other people who may be worse than me or the same as me, I don’t want to know how that works out, I don’t want to know how it’s going to be later on” ” (Jane, p.6)

It was felt that the attempts to predict the future are not necessarily helpful to sufferers:

“There are great dangers in continuously thinking about a future which can’t be predicted and missing out on the fact that life’s happening for them now” (Gareth, P.10)

3.4.1.2 Emotional strategies

Professionals felt that sufferers make attempts to maintain their sense of self in order to manage emotions around their dementia.

Searching for meaning

It was felt that couples tend to seek new meanings around changed circumstances in a variety of ways. For example, in trying to make sense of the changes, it was noted

that people will try to seek answers about their condition and why it happened to them:

“They want to know why, because to say “this is just a random piece of misfortune, too many variables to explain”, is not very satisfying. People want the thing they can pinpoint ... It’s a terrifying thought that the world is a random place of unpredictability. A certain sense of controllability is a more comforting construction than “its just random misfortune” ” (Gareth, P.10)

Some professionals felt that sufferers found value in the use of the label ‘dementia’ in externalising deficits, or viewing the dementia as being separate from their identity.

Two professionals described particular examples of this:

“Part of it is negotiating a language for the dementia with someone, the way they talk about it. Starting to talk about it as something, even if it’s putting it there in front of them rather than being part of them, this is something which they are then dealing with. With this person ... they wanted a copy of their CT scan, which they have on their wall, and they look at it. They talked about the head, “it’s not my fault, it’s the head” ... It’s about us taking away the blame, “this is happening to me but it’s not me, I am still me”, it is separating out the problems” (Heather, p.11)

And

“I’ve seen a few clients who have adjusted well and who are coping very well. I’ve got a client who’s got a diagnosis of posterior cortical atrophy and she’s very insightful and aware, and talks about “Not Today Mr Alzheimer’s, I’m on top of you” ” (Ian, p.8)

Comparing with others

Professionals reflected on people’s tendency to compare themselves with others. In this context, they mainly referred to peer groups of dementia sufferers or groups of sufferers and partners:

“You have to be very careful about who you bring together, ‘cause you will find that people will compare ... there was one woman saying “oh so and so over there, she’s just had her Aricept increased by 10mg, that must mean that she’s getting worse. I can see some of me in her and does that mean I’m getting worse?” ” (Gareth, p.11)

However, it was felt that contact with others can also be beneficial in terms of making sense of their situation:

“There’s concerns about what’s it going to be like seeing people worse off than me, or the fact that people might feel very shy or very anxious about being in a group with different people. Time and time again people have had those concerns, but actually found that it’s been fine” (Heather, p.13)

And

“I think some younger people think it is so rare and don’t know anybody else that this has ever happened to ... until they are introduced to a group of people who have it. I think that, for most people that can be quite helpful in making some sense of it” (Jane, p.8)

Maintaining identity

Part of the process of adjustment to a dementia of may include a negotiation of the person’s identity, and finding values and strengths that can endure:

“How can we build on the strengths the person has, and create conversations about where that person can succeed? ... I have used the metaphor of ‘Dancing with Dementia’ rather than the metaphor people commonly have about ‘trying to beat it’ ... Thinking about how to gracefully let go of what I am really struggling to do well anymore, but maximising the things I can do? It’s more about drawing out other values that have always been there. People might have been more inclined to define themselves in terms of their earning capacity, but perhaps there has been a value of being a good friend, or of being a good listener but they have been less dominant or less talked about or not seen as so valuable” (Heather, p.9)

Some people may try to draw on coping skills they have used in the past:

“People who have always been quite positive in their lives in other ways, and who have been through other traumatic events, or illnesses or bereavements – they find some parallels which can be helpful” (Heather, p.10)

Past coping skills, however, were seen to have somewhat limited value and sometimes it was difficult for sufferers to come to terms with not being as able as they previously were:

“Frustration, definitely, ‘cause people can’t do things and they know they can’t articulate. Some people try and do things, like make me cups of tea with Bovril cubes ... People try to do things and make a total disaster, set fire to the cookers. One gentleman, you wouldn’t have said anything was wrong with him, he could still operate a lathe and make things. But he did deteriorate, he didn’t admit that, saying “there’s something wrong with the lathe it’s not cutting properly”” (Keith, p.7)

Holding on to control

Some professionals had experienced sufferers talking about ending their lives. However, this was often felt to be part of sufferers’ attempts to retain control of their situations rather than indicating concrete plans for suicide:

“There’s a lot of talk about Dignitas and assisted suicide, people get into that kind of conversation. “I’m going to end things before it gets to this” ... When I

was working in the older people's mental health team, those conversations didn't seem to come up. Now I'm working with a younger group, that is a theme that comes out" (Gareth, p.8)

And

"I've had a client talking about ending his life at a time that's right for him, 'cause he does understand the diagnosis, and what it means for the future" (Ian, p.13)

3.4.1.3 Practical strategies

Many couples reconsider where and how they live in relation to coping with dementia. For some this means moving house to minimise housework or to live closer to family:

"I know a few couples where the well person has gone part time working or spent more time at home, or even stopped working altogether to do the caring role, even if they hadn't meant to do so. People have moved to be nearer family, or to have a smaller house - a more manageable set up. Some people have called in friends and neighbours to help and cope" (Jane, p.6)

And

"There's lots of people who have talked about moving out of the family home, for different reasons, it's just got too big for them to manage, or ... they are having difficulty with the stairs now. That's a huge thing, most people that I've worked with have lived in their homes for a long time and they're talking about getting a smaller bungalow, and being able to cope with that" (Leanne, p.8)

Keeping going

It was felt to be important that sufferers, with the support of partners, kept engaged with, and distracted by daily activities as far as possible. The value of keeping going seemed to be particularly in doing things that supported the sufferer in feeling useful and validated:

"People find it helpful if they are given as many opportunities as possible to keep doing as much as they can. I'd be struggling to think of anyone I have worked with who wants to sit back and give up. Most people, whatever state they are at, however their illness is affecting them, say "I want to continue to do the things". Not just what they enjoy, but things that are valuable or helpful to other people" (Heather, p.6)

Talking to others

It was felt that peer support groups were instrumental in helping sufferers to share their feelings, and that there was usually a positive impact from communicating in this context:

“Some of the best emotional support comes from meeting other people who know what they’re really experiencing and talking about. People really benefit from meeting other people at a similar stage of the illness, support groups are phenomenal. As soon as you get people in the room, they’re sharing thoughts, feelings, recognising what the other person’s saying. You can feel it and see it, the amount of support people get from knowing “I’m not alone in this, other people are experiencing this too”. They understand in a way that professionals simply can’t” (Gareth, p.10)

And

“People who show interest in groups often recognise that it might be helpful to talk to other people, to make some sense of what is happening to them. That can be quite positive” (Heather, p.5)

Professionals identified a number of specific benefits that people derived from engaging in peer support groups:

“The things that people involved in therapeutic groups talk about are the opportunity to normalise what’s happening, the validation from people in the same situation, being in a situation where they’re not the one being cared for. They’ve got equality, they are able to be in a more reciprocal relationship than they get to experience outside of that group. There’s a lot of dignity in that and in being able to give advice to someone else” (Heather, p.12)

However, some professionals felt that sufferers sometimes actively avoided engaging in supportive conversations about their situation:

“Most of the time they really won’t talk, there’s a couple that are aware that they have a condition and that’s why they see me, but even then they don’t really talk about it, they don’t want to talk about it” (Leanne, p.4)

A variety of strategies were reported, mainly around sufferers seeking to retain a sense of control, and partners seeking to maintain a sense of hope. Sufferers and partners may seek to negotiate their identities to include the dementia. The benefit of peer support was raised as a major factor in helping many sufferers, and partners, to cope.

3.4.2 Theme 2: Factors affecting coping by sufferers and partners

Individual factors	Emotional reactions Impact of the dementia Hopes and expectations
Relational factors	Impact of role changes Effect on couple relationship
Systemic factors	Impact on multiple generations Isolation Societal values

Although individuals and couples cope in different ways, professionals noted a number of key factors that may affect that capacity.

3.4.2.1 Individual factors

Emotional reactions

Professionals discussed that sufferers and partners respond to a diagnosis, and the resulting changes, with a range of emotional reactions:

"[Younger] People cope in lots of individual and unique ways. Sometimes there's a denial type of response, and some anger about the diagnosis. It's a bit like any bad news isn't it, coming to terms with that and understanding it" (Ian, p.6)

Most professionals felt that younger people may react quite differently to older people to a diagnosis:

"In younger people particularly there's a sense of disbelief, shock, trauma" (Gareth, p.10)

Frustration experienced by many sufferers was identified as a clear issue in working with younger people:

"With younger people, there's more of a frustration, quite a few anger issues, whether it's from frustration that they can't communicate ... I have been shouted at by 90 year olds in the past, but it's a different level ... I do notice that as a difference, yeah. It's more of a challenge ... I do notice that people can change quite quickly whereas older people ... don't seem to have that frustration and aggressiveness" (Keith, p.5)

Fear of thinking about the future was also a theme raised as pertinent to some younger people with dementia:

“A lady I see in clinic who we’ve offered a lot of support to - I think she’d benefit greatly from the supports we offer. She’s absolutely terrified of meeting others in similar circumstances who may be more advanced in their illness than she is, she’s terrified of seeing what’s to come, seeing other people’s problems and needs” (Ian, p.7)

Professionals felt that younger people were also fearful of being seen as ‘different’ by others, which affected their social lives:

“They think they can’t do these things any more, they can’t go out. I’ve got ladies that don’t want to go out because of toileting needs, they don’t want to spend time with old friends and they get nervous about that, and then the carers get nervous for them” (Leanne, p.9)

Impact of the dementia

Professionals felt that dementia may place a unique challenge on sufferers’ coping skills:

“People tend to say it’s different ... with dementia you can’t see it, it’s not something concrete. It’s harder to explain to people, more abstract. There are things that people draw on, but I also hear from people it’s different, it doesn’t translate easily. There might be things we can take from it and use, but it’s not an easy switch” (Heather, p.11)

It was also felt that dementia impacts on ways that sufferers may have managed personal trauma in the past:

“People who have had other stresses or life events that are complicating the picture, earlier trauma that that person might have managed quite well early on ... With a memory problem on top, they’re not able to manage in quite the same way. So that problem is interacting with problems brought about by dementia” (Heather, p.1)

Additionally, difficulties in communication were identified as a particularly challenging issue for younger people:

“We’ve seen people with more rare forms of dementia. We’ve got quite a few frontotemporal dementias on our caseload, more than you’d expect to see in an older cohort. The communication difficulties that some of our clients have are very profound and disabling in terms of their ability to express their needs and their wishes” (Ian, p.7)

One professional discussed the particular communication issues in younger people as perhaps presenting a training need:

“Communicating with people with dementia is the thing I find most difficult. I’ve got a lot of people who have quite difficult communication needs. Sometimes if you’re not having the right kind of day yourself ‘cause you’re on all the time, this constant performance, it can be very tempting to just give up and have a really quiet session with somebody ‘cause communicating’s so difficult. So I think training around communication would be really helpful” (Leanne, p.11)

Hopes and expectations

Some professionals felt that many sufferers and partners hold high expectations of medication and of what services can deliver:

“Sometimes people have high expectations of the medication, what services can do. Sometimes that is an issue” (Ian, p.6)

One professional described her thoughts about the benefits of medication, alongside the difficulty of balancing expectations:

“I think you would be offered medication quite early to try and prolong the good times rather than go downhill more rapidly ... People these days think “there is a tablet for it, so you will be ok”. We have to be very careful to explain “this isn’t going to work for everybody, maybe you are the one person that it’s not going to work for” . You have to be very honest when you start prescribing that it’s not going to be a cure. But I have seen some wonderful improvements with medication. Although you know it is not going to last forever, it makes their life more worthwhile for the time being” (Jane, p.7)

The process of adjusting expectations of the future was also identified as a difficult area for professionals:

“People ask what’s going to happen in a year, two years, or five years, and how long will they live for. It’s very difficult to answer those questions, because you know every person’s unique, no situation’s the same, the illness affects people in very different ways. So you find yourself making those stock phrases to people “take it a day at a time, live life to the full, try not to think too much ahead, plan for tomorrow”. But who knows what it’s going to be like in a year?” (Ian, p.6)

3.4.2.2 Relational factors

A number of factors specifically within the couple relationship were reported to affect coping and adjustment.

Impact of role changes

It was noted that some couples tend towards overprotection of the sufferer, compensating for deficits or attempting to safeguard against mistakes or forgetting:

“I’ve seen some couples where the carer is beginning to do too much, and making the other person feel undermined or deskilled ... they want to protect the person, make sure they’re safe, safety and risk is a big thing. Maybe a person on the receiving end feels that this is overbearing and “I do need some help but not to this extent” and then tension builds” (Gareth, P.13)

It was reported that the balance of providing help and support, and maintaining independence, was a difficult one for many families:

“One of the things that families struggle with is not expecting too much of the person, but not trying to protect them too much either. A really common thing is wanting to maintain independence and continue to be useful, taking great pride in situations where they can be useful. So that frustrates, where people think things are being taken away from them or they are being mollycoddled. It’s a very hard balance for carers and families to get right, it’s a very common complaint” (Heather, p.6)

One professional described the difficulty experienced by sufferers in this position:

“I think people get frustrated when somebody’s doing everything for you ... there’s huge amounts of boredom. People are just sitting there all day sometimes and they are very bored” (Leanne, p.8)

However, it was felt that the absence of any attempt at adjustment also resulted in difficulties for some families:

“Some families, you find there’s an over adjustment, or over coping, which becomes almost toxic to the person with the illness, they find it too much. In some situations there’s not much adjustment at all, there’s just hoping “we can carry on as we are”” (Gareth, p.14)

It was reported that some partners may withdraw emotionally from the sufferer as a preparation for future bereavement:

“There is this need to ... separate themselves off, in order to survive. You can’t be with that 24 hours a day, 7 days a week. They are going to be bereaved. It is almost as though it is self-protection, to separate yourself from that person at some stage, just gradually withdraw when they become not themselves anymore and their personalities have changed. “It isn’t the same person anymore, they don’t mean the same to me as they used to, and I have to pull myself back a bit”” (Jane, p.14)

Effect on couple relationship

The shift to the 'carer' role can cause additional stress for some partners, resulting in further changes in the couple's identity, which may in turn affect the marital relationship:

"One thing that we tend to shy away from, and I think it needs quite a lot of thought, is the marital relationships as well, husband and wife and how they may respond to each other when one of them has a diagnosis of dementia. It is not very often that we actually broach it with anybody, and I think it is probably we are all a bit shy and embarrassed to do so" (Jane, p.12)

One professional described a conversation with a partner about this topic, and concerns about the implications of the change in relationship for younger couples:

"I did talk to one lady whose husband had dementia, and I asked 'how has it affected your marital relationship?' She said "I can't think of him in that way anymore because I am doing so much for him, I am his carer rather than his wife and I don't have that same sort of feeling about him anymore". It's much more pertinent to younger couples, where normally, they would be expecting to carry on a normal married life, but then somehow things have changed, they're having to perceive each other as quite different" (Jane, p.13)

Suggestions for helping to manage the stress between couples included the couple engaging in enjoyable activities together:

"I know what a positive reaction I get [from activities], and it would be lovely for them to have that positive reaction. Because I think, sometimes, there's a lot of tension between the carers and frustrations from both sides really, so it'd be nice if they could do these activities as much as possible" (Leanne, p.10)

Half of the professionals described gender differences in coping styles within couples, and common themes such as male partners wanting to have concrete solutions to their concerns:

"You do see a lot of men who spend a lot of time looking at the treatment plan, and this is about finding the answer, becoming almost obsession about how many milligrams this week compared to last week. You know, like the answer lies there, in terms of treatment and having answers - a very functional approach really" (Gareth, p.13)

And

"It's very different when I speak to the husbands, they want solutions to things ... the wives want to talk at length about things. I get "this is the problem, what's the solution?", it's very specific. It will generally be "she has become incontinent, or she no longer is able to feed herself, what do I do about it?" It's very problem solving" (Leanne, p.6)

3.4.2.3 Systemic factors

Impact on multiple generations

Professionals described ways in which the particular impact of young onset dementia affected all generations of the family:

“As opposed to the work I did in older people, there’s a huge sense of loss in the families, because they’re younger and generally most of the people are getting towards retirement and had lots of plans. So there’s a big sense of loss. You can see this sense of loss with the children, with their parents” (Leanne, p.6)

And

“Younger families may have younger children leaving home and making their own relationships. I suppose they feel very torn between living their own lives and supporting a mother or father with dementia. There is a whole layer of family support that’s missing. And the other generation affected is the parents of the person with dementia. Very often they have parents who are in their 70’s or 80’s, and see a child with dementia at the age of 50. That is very very distressing for them, “why has it happened to them, it should be happening to me” ” (Jane, p.4)

Some professionals reported that family members often have differing needs and expectations, many of which may remain unspoken within families:

“Families that don’t want to talk about the diagnosis or the future, classically families go “oh, that’s not gonna happen” or “don’t worry we don’t think about that yet”. All those protective things which are intended to be helpful, but actually people often find very unhelpful, and want to be able to sit down and have frank discussions. Often, that’s about wanting to take care of their family and wanting to leave things in order before it’s too late, those kinds of issues, but families often are understandably reluctant to have those conversations” (Heather, p.6)

Isolation

Some professionals reported that these difficulties may lead to sufferers becoming isolated from members of their families:

“We have come across couples where a son or daughter, perhaps in their early twenties, distanced themselves because they just don’t want to think about it, and they don’t want to be facing up to it. There is a conflict in the patient and their partner as well, because they don’t want to make a burden of themselves. But they do feel hurt that they are not getting support from people who could give it” (Jane, p.3)

Professionals reported that younger couples were more likely to become socially isolated:

“Most of the clients we get, the one thing you get is social isolation, ‘cause you find friends drift away, people can’t cope with it and so they’re isolated. Most of what I get is “oh great, we’re going out, oh thanks for taking me out”” (Keith, p.15)

Isolation was thought by professionals to be partly due to fear or uncertainty of people around the sufferers as to how to cope with the changed person:

“A lot of people lose friends because people do not want to be embarrassed by things going on, or they don’t know what to talk about, or can’t cope with the repetition of conversation or the odd behaviours that may happen. They just slide away, and that can be very hurtful” (Jane, p.6)

There was often an adjustment in people’s social lives, and a move towards socialising in circles where their dementia is known, accepted and supported:

“Lots of people that go to the Alzheimer’s groups, the singing group and dementia cafes found it really difficult to begin with, making friends with people, spending their social time in dementia centres. It took them a long time to come to terms with the fact that they were going to find a little bit of respite there, a lot of help. Most of the people that have done it, it really works for them, they’ve met other people, they find support from the other partners” (Leanne, p.9)

Societal values

Some professionals reported that pervasive societal values about achievement and success led to negative perceptions about dementia, and often affected sufferers’ ability to cope:

“The way people view themselves, what it means to have a dementia and what is seen as valuable in our society, like achievement and success, being quick. It’s very difficult to start thinking those are the very skills people are learning to let go of and to start to value other things that aren’t valued by society. Relationships and emotional connections they can still enjoy ... but it is quite a difficult transition. The stigma if they own up to the diagnosis, wanting to put the message out that people with Alzheimer’s disease are not to be feared and can still function, but at the same time risks people treating them as if they are incompetent. More information, more positive images of dementia, better understanding that dementia doesn’t equal being a vegetable in a chair” (Heather, p.8)

Values in the workplace were also felt to have had a negative effect on many younger sufferers:

“People have lost their jobs or been sacked ... sometimes before they get a diagnosis. It’s only afterwards it becomes apparent that they weren’t doing very well because of their diagnosis, but people have been sacked because they are not coping or not able to learn this new computer system. So they are put on the scrapheap” (Jane, p.5)

Professionals reported multiple levels of factors which can affect the ability of couples to cope with dementia. The risk of isolation was felt to be high for younger people.

3.4.3 Theme 3: Contextual factors in working with younger people with dementia

Challenges for professionals	Identification with service users Dealing with uncertainty Professional impotence Coping strategies
Service challenges	Diagnosis issues Service dilemmas Societal view of dementia
Supporting coping processes	Informational support Supporting independence

3.4.3.1 Challenges for Professionals

Professionals spoke about working with people in their own age group with dementia, and the unique impact that this has on them personally and professionally.

Identification with service users

Most professionals felt that a large part of the impact stemmed from identification with the sufferers, due to similarities in age or life stage:

“There is a particular issue around working with younger people, I’m seeing some people now the same age as me. With older people with dementia, the age gap, so you can psychologically protect yourself thinking “oh well that’s much older” ... When you sit across from somebody roughly the same age as you, the empathic leap of imagination is not wide at all ... the psychological impact on you is more profound” (Gareth, p.17)

And

“The age thing is an interesting point. I’m working with 3 people under my age and I’m only 50 - I’ve got 3 on the caseload that are younger than me. And I suppose the way you cope with that is, “there by the grace of god” you know, and get on with it, yeah. I suppose it makes you feel like you want to do a good job by people that are in your care” (Ian, p.10)

Specific issues were noted, such as having young children, driving, or working, that further strengthened the identification:

“There are people who have touched me emotionally. For me, it’s often things that touch on relationships with their children or grandchildren, which I find more distressing because I have younger children. So it’s necessarily about an age thing, and identification that way ... there is something particularly distressing about seeing someone who’s declining and losing abilities very quickly and still quite young” (Heather, p.4)

And

“Some of the difference is my own age in relation to the patients. When I was working in older people services, they were older than me (laughs) and now, because I am getting older as well, a lot of them are younger than me and that gives you a different perspective on things. When you see people who are younger than you are or the same age as you ... then “that could be me” or “it could be my husband”. I think that affects you more actually, it didn’t seem to affect me by thinking “oh that could be my mother or my father”, but it does more when it is your own age” (Jane, p.2)

Some professionals described working with younger people with dementia as being a reminder of their own and others’ mortality:

“Makes you feel a bit mortal ... And it makes you feel very sad, ‘cause you see the carers, they’re quite often younger than the clients, so they could be in their late 40s or early 50s. You think, well you know, 50 years old, you should be enjoying life, and there you are caring for your husband, partner, who’s not going to get better” (Keith, p.10)

One professional felt that the distress felt by staff working with younger people with dementia was an issue for services to be aware of and to prepare for:

“We’re all feeling distressed by observing deterioration, and sometimes the rapidity of that deterioration and sometimes people’s deaths. We’ve had a number of clients already been through the service and died. That’ll be a familiar part of our work” (Ian, p.10)

The emotional impact also resulted, for some professionals, in a shifting perspective on their own lives:

“Some of my clients are younger than me and I find that quite scary, it’s changed my attitude to life. I think, “do it now”, in 5 years’ time you’re going to retire and go to Spain, and I think if you’re going to do it, do it now. I’ll be 60 this year and all my clients are the same age or even younger, I think “this time next year that could be me” ” (Keith, p.10)

Dealing with uncertainty

Professionals acknowledged the difficulty they felt regarding their inability to provide answers in the case of young onset dementia:

“I think about the difference between mental health and physical health. Someone’s got a broken bone, we can give you the reason why, this is the treatment and prognosis for the broken bone. But with mental health we just don’t know what the problem is and we don’t know what treatments are going to work, and we don’t know the reason for it. I think that everyone tries to search for a reason for things, and when its mental health and there’s not any reason I think that’s a really difficult thing” (Leanne, p.14)

Some professionals felt that they were under pressure to understand the condition, or to be able to provide answers:

“I keep thinking there must come a point where I’ve got enough understanding to be able to do something, rather than still trying to understand, you can’t stay like that forever. But it is a process of learning and not to be too hard on yourself if it doesn’t make sense by next Wednesday, ‘cause it won’t. People will come up with a dilemma, try to put an expert hat on you. They want you to say “if you do this, that’ll be the answer”. You have to be wary of that, it’s part of the dynamic. They go and see the expert, and it’s quite a passive relationship” (Gareth, p.19)

The unpredictable nature of young onset dementia also left professionals feeling challenged:

“You do get moments of remarkable clarity with people, it’s quite scary. Someone who’s talking complete rubbish for an hour and a half suddenly will say something really sensible” (Keith, p.6)

This was reported to be qualitatively different for younger people than older people:

“It’s [young onset dementia] a completely different ball game than working with older people with dementia. It’s completely unpredictable, we try and risk assess but it’s really difficult because it can be so different from day to day” (Leanne, p.3)

Some professionals felt that acknowledgement of their inability to provide answers was an important part of working with younger people:

“It’s a balancing act between being honest, open, recognising the stress and difficulties, but also spending time thinking about what they can do, their strengths. The question people ask is “how long have I got to live?”, You can’t answer that, you can’t soft soap. It’s about being honest with sensitivity, but also open about “we don’t know”” (Gareth, P.12)

Professional impotence

Some professionals felt particularly powerless to help people, within the limits of current services available and given the incurable nature of the condition:

“You begin to feel quite impotent really, as a professional, about what you could offer people. ‘Cause often as a worker you’re only as good as the services you can access” (Gareth, p.6)

And

“I think “oh what can I do”, sometimes you have to be quite hard I find. I have to say “right it’s a job you know”, you can’t go “I’ll make it better”, sometimes I think “well do what you can and you can’t carry it” ” (Keith, p.11)

The sense of impotence may, however, lead professionals to talk to sufferers in ways that could minimise or invalidate the impact of their dementia:

“The temptation for us as professionals is try and say “it’s all ok”. Actually obviously it isn’t, and so it’s getting that balance between sitting with that person in the shock, pain and distress, whilst also helping them to hold on to what can be ok, and the ways to have quality of life. I think perhaps we try and do the “ok” bit too early ... I think a lot of that ‘trying to make it alright’ is for our benefit” (Heather, p.14)

Coping strategies

Given the emotive and complex nature of working in this field, all professionals discussed the importance of having strategies for managing the personal impact.

A fundamental element of supporting themselves in their work, for all professionals, was making use of available supervision:

“Supervision is absolutely key, regular supervision, we have really great supervision levels. We have team meetings, psychology supervision, joint supervision, personal supervision, so many options for supervision! It can get very lonely, and you’re doing really difficult stuff all day. Sometimes, even if I see my line manager, I might just spend half an hour offloading to him. ‘cause its just key. You’re on the ground making decisions constantly and that can be really difficult - you start worrying whether you’ve made right decisions, you haven’t really got time to think and reflect” (Leanne, p.11)

Peer support was also felt to be essential, and professionals felt that they gained great benefit from sharing experiences with their peers:

“Peer support is good already, but you know can be enhanced when sharing a base. We have a fortnightly team meeting and we have a psychological support session. I think all of that is helpful, but then there’s the one to one stuff when we’re able to talk to each other about “this happened and it upset me”. Sometimes our ability to respond might be reduced, so our need for support may increase over time” (Ian, p.10)

And

“You do feel you have good support and help, I think that’s essential in any care work, that you can offload to sympathetic people” (Keith, p.12)

Half of the professionals discussed the importance for them of maintaining a good work life balance and boundaries, and described the personal strategies that they had developed:

“I did struggle in the early days. I used to get quite attached to the clients, and I used to struggle. Now, my coping strategy is to switch off by walking the dog, or switch off by my hobbies and stuff I do ... this has taken me probably about 2 or 3 years to achieve” (Keith, p.11)

And

“We’ve talked a lot in supervision about the potential for burnout, it can get really weary. We talked about managing our leave so you know we’re not ‘on’ for a really long time before we take a block of leave. ‘Cause once you do have some time away you come back replenished” (Leanne, p.12)

Maintaining awareness of feelings and a realistic professional perspective were also seen to be vital considerations:

“Take a bit of time mapping out what [services] is in existence, where the gaps are. Talk with plenty of people with experience, and don’t go rushing in thinking you’re going to have all the answers overnight” (Gareth, p.18)

And

“I think “well I only have them for 2 hours, I can take them back then”. So why should I moan (laughs), I can walk away from it, the carer can’t” (Keith, p.17)

3.4.3.2 Service challenges

Professionals identified a number of challenges to effective provision that they had encountered within their services.

Diagnosis issues

Some professionals discussed the challenges generated by the necessarily thorough and prolonged diagnosis of young onset dementia:

“Often the prodromal signs take a while to set in before it becomes apparent that anything is seriously wrong ... people are thorough about trying to diagnose a young person, to hope it isn’t, so they try to find other reasons that cause these symptoms ... they think we must try and get this person better or else we’re condemning them to an awful life so there is a lot more thoroughness probably” (Jane, p.7)

Due to the relative rarity of young onset dementia, there was thought to be a difficult balance in increasing awareness of the condition. Professionals were concerned that perhaps greater numbers of younger people may present to services thinking that they may have dementia, but care needed to be taken not to discount any likelihood that they may have it:

“A lot of people have memory problems and think it is Alzheimer’s disease. So a lot of people you see presenting, of course, won’t have anything like that going on at all. Everybody is stressed and can’t cope for any number of reasons. But within them there is a proportion where this is a very real issue” (Heather, p.2)

Service dilemmas

Professionals felt there was often a great deal of inconsistency in levels of service provision experienced by sufferers, generating confusion:

“If you think of someone’s journey through services, or health and social care, they might see a neurologist or the memory team, they might have involvement then with a nurse, or need a social care package. They’ll perhaps see a psychiatrist, OT’s and physio’s. So there’s lots of professionals involved, and maybe in the latter stages of the illness they’ll meet continuing healthcare criteria. So, across the course of somebody’s illness, there can be a lot of different professionals coming in and out” (Gareth, p.1)

Professionals acknowledged the difficulties in placing younger sufferers on inpatient wards, especially in terms of the different physical presentation of a younger person with dementia:

“Big gap ... in inpatient services it’s a real difficulty. If people need acute assessment, they have to come to a ward with people old enough to be their parents or grandparents. Younger people with dementia, who are challenging or complex, sometimes pose a risk to the frail and elderly. We’ve had incidents resulting from inappropriate patient mix ... [a patient] is physically very healthy, very strong and able but mentally is not as strong and able, and she’s become violent and aggressive. When we’ve had inpatients we’ve had occasions when people have been at the level of challenging behaviour and psychiatric acuity of needing a psychiatric intensive care unit, which we don’t have available” (Ian, p.5)

There was often a dilemma for services about where to place sufferers, depending on their level of functioning:

“There is a huge gap in the service, and one that we would like to remedy. If they are at a stage where their insight and understanding of what’s wrong

with them is very limited, and they need practically everything doing for them, then I think their needs are quite well met on an older persons ward. It is more difficult for the families to come to terms with that than the patient themselves ... If they are aware, and if they seem to stick out like a sore thumb, then you have to negotiate with younger adult wards. Again, they may not fit in very well, but at least they are with their age” (Jane, p.9)

Societal view of dementia

Four of the six professionals discussed their feeling of there still being a strong societally held presumption that dementia was only relevant to older people:

“You’ve always known that older people might have dementia, we’re more accepting of it and things happen as you get older” (Leanne, p.14)

However, it was felt to be important to recognise that the needs and expectations of younger people with dementia are different, without overlooking the needs of older people:

“I am a little reluctant saying there is more need for younger people. In some ways there is, but I would say the need is very great in older people too, and that tends to be under recognised. I feel a little bit reluctant to go into about why it’s much worse for younger people, there are many things that are similar, many frustrations that people with dementia would share whatever age they are” (Heather, p.3)

3.4.3.3 Supporting coping processes

Professionals discussed a variety of ideas for supporting individuals and couples.

Informational support

Provision of information was felt to be an important consideration, particularly in terms of professionals using appropriate language and communication:

“It seems helpful to go out to people at least within a week or two of the diagnosis, to go over things again, pick up questions that would have occurred since the appointment. Because any of us going to a medical appointment come out forgetting most of what we’ve been told, but obviously people with dementia are so much more on all levels, so that initial support is important” (Heather, p.13)

Information and support provision was felt to include a need to ensure clarity about the diagnosis:

“Somebody in clinic said “we’ve been told its Alzheimer’s, but now you’re saying you’re from a dementia service, is Alzheimer’s dementia, I thought they were different?” So that basic lack of knowledge and understanding

emphasises the need for good communication, also the need for education and psychological support around the illness” (Ian, p.5)

It was suggested that a younger person will have different support needs in various areas, and that professionals need to maintain awareness of this. For example, caution may be needed in suggesting they access support groups:

“How can I suggest this person goes along to this particular place, when the people they’re going to be with are going to be 20, 30 years older? They’re going to run in terror through the door really, thinking this is totally inappropriate for me ...what they need is emotional support, information. They need to know there’s somebody they can call” (Gareth, p.2)

Financially-focused informational support was also felt to be paramount for younger people, who may have still been working at the time of diagnosis:

“It is the sort of things you think about generally, e.g. for things like work and benefits and things they might need which are quite different to when they are old. There are quite different sorts of benefits to be had, I really don’t know much about the younger onset dementia benefits ... there is a whole different aspect of what they might be entitled to, which I think people probably need training in if they are working in that field” (Jane, p.10)

Some professionals talked about developing written information specifically for this client group, and the considerations they thought were important for this:

“Get empathy into it ... As a way of trying to have a welcoming service if you like. As opposed to something people would be frightened of, which can easily happen when you use too much technical medical language” (Gareth, p.4)

And

“Maybe there’s something we could provide, a very easy to read thing about the illness, but also about other issues like driving, like making an advance decision, like LPA [Lasting Power of Attorney]. Those sorts of things, if addressed at the outset, can make life a lot easier later on. I think that would need to be done very carefully” (Ian, p.12)

However, it was felt to be important that support took account of timeliness from the sufferer’s point of view:

“Generally people have to come to that in their own time. People are rarely ready to use all of that at the beginning, they need time to get over the initial shock” (Heather, p.13)

Above all, the professionals indicated the need to use person-centred information in individual formulations and interventions:

"I have tried to keep the person central to the whole assessment process from the outset, whether or not we think they have a dementia. Checking out what they want to know, what knowledge they are coming with, so we can pitch things appropriately for them throughout the process ... Not making assumptions, because a diagnosis can mean anything from relief and very positive, through to shock and trauma. I think we can't go far wrong if we think from the beginning what it means to this person, what might they make of this" (Heather, p.15)

And

"Some people aren't up for that very open conversation about things which are very profoundly affecting them. You have to work at people's pace and respond to what discussion they want to have, rather than the discussion you want to have" (Ian, p.7)

Supporting independence

Some professionals felt that their role was to support people to retain their independence via person centred care:

"There are specific ways in which the condition might make certain things difficult, but on the flip side, dementia doesn't affect many skills we retain, many bits stay the same. How can we capitalise on that?" (Heather, p.14)

It was felt, however, that support should be dependent on what the person was able to accept at a given time:

"There is a whole variety of attitudes to the support that is available. Some people struggle on and manage well, and others struggle on and don't manage well, but are still very resistant to the sort of care that is out there" (Jane, p.6)

It was felt that age-appropriate activities needed to be included within services:

"Their experiences have been different, things they might like to talk about in reminiscence may be quite different to reminiscence for a 70 to 80 year old ... It might be pop groups, or concerts you have been to, or foreign holidays, things like that, which are quite different for younger people than older people. More will have been to university, will have been in different jobs" (Jane, p.11)

Maintaining awareness of the cohort differences was felt to be essential in encouraging people to feel comfortable within services:

"We had our young onset club at the day hospital and were choosing a theme tune for the group, and the songs had to be of the right age cohort ... in older people's services, we tended to look at Vera Lynn. Last night we were looking at Queen, The Rolling Stones and U2 - those differences are very important to attend to" (Ian, p.9)

Professionals felt that they were able to retain a positive view of the sufferer by using person-centred, flexible approaches:

“There would be things about how to continue to build on strengths and to keep going, to have a conversation on ways in which the dementia changes things, but also doesn’t change things, which is quite an important discussion early on” (Heather, p.14)

It was also felt that sufferers’ confidence could be maintained by a balance of activities, including everyday, typical pursuits:

“I think it’s important to keep things in mainstream activities, so I try and say “well, we’ve done this today, we’ve been to Asda and we’ve been fine, we’ve baked a cake and we’ve been fine”, we’ve done these things that, you know “normal” people do” (Leanne, p.10)

Some professionals remarked on the greater use of technology and independent information seeking by younger people, and it was felt that this is beneficial:

“People often come to clinic saying “I’ve looked on the internet, I’ve read this book, I’ve looked at this medication, I’ve spoken to other carers on blogs”, and that’s interesting, people perhaps are better informed? I’ve got a client in a residential home who’s becoming more impaired, but he’s using his mobile phone and his iPad. The home staff have never seen this before, so they were a bit like (laughs) “oh right, how do we respond to this?” But that’s just part of his everyday life, and he’s still cognitively able to make use of those resources” (Ian, p.9)

Use of technology was felt to be something that services would increasingly need to incorporate:

“They have computers, practically nobody in old age services would know how to use a computer, but all these young couples are using computers and iPhones and God knows what. That sort of thing we would need to get to grips with” (Jane, p.11)

Technology-based information seeking was also reported to be helpful for partners:

“One of the husbands says that he’s found absolutely everything out on the internet, how to cook, how to use a washing machine” (Leanne, p.7)

Despite the challenges, all professionals expressed enthusiasm about working with people with young onset dementia:

“I just find it a very satisfying and fulfilling job, to be honest” (Keith, p.16)

Particular reward was gained from the sense that professionals could make a difference to the quality of life of sufferers and partners:

“It’s a great area to work in. It’s a developing service, there’s a lot that can be done to improve people’s quality of life, so making that emotional and time investment can actually make a huge difference to people’s lives” (Ian, p.11)

And

“You can’t help but feel pleased that they’re getting something out of it, you know you’re making that bit of difference. That’s the thing that I always try and focus on really, even though it’s such a sad situation. If we weren’t here it would be an even sadder situation ... it’s a really challenging job but really rewarding as well, and there’s not a day goes by where I don’t learn something” (Leanne, p.16)

Professionals reflected on the whole course of someone’s dementia, including the possibility of future inpatient admissions and the challenges associated with that for younger people. The challenges for professionals were multi-faceted but balanced by the effective use of supervision to manage feelings of identification with the sufferer and limited availability of appropriate services.

3.5 Summary of results – professionals

The views of professionals working with young onset dementia gave insight into the unique challenges of working in this field. In particular, they highlighted aspects of responses evoked in them personally, provided an objective context for examining coping strategies used by sufferers and partners, and by the professionals themselves. Discussions about the need to consider each case in a person centred way led to considerations of the experiences of service users, and how services could create information and support services to younger people.

3.6 Overall summary of results

The process of examining the separate perspectives of couples and professionals highlighted diverse emotions, dependent on how willing and able the couples were to adapt to change, the level of support they received, and feelings and presumptions about dementia and disability. Coping strategies within couples varied between negotiation of changing roles, responsibilities and activities, and holding on to a fixed or enduring view of self and identity. For professionals, emotional responses mainly centred around identification with service users in terms of similar ages and life circumstances. Coping for professionals included a focus on the need for good supervision, peer support and work life balance.

Some overlapping themes emerged between the couples and professionals results. In particular, there were shared emotions of shock and frustration, and reporting of the need to keep perspective and focus on the present. There were also similarities in the perceptions of couples and professionals about coping strategies used by sufferers and partners, such as the use of uncertainty in diagnosis to hold on to hope, and the acknowledgement of a general societal view that 'dementia only happens to older people'.

These interviews emphasise the importance of individual differences, the relationship between the couple involved, their personalities, expectations, hopes and fears. The interviews also highlighted the need to consider and appreciate the differences in coping with information and experience. There were varied experiences and feelings about support, with some suggestions for services and information provision, although overall the couples appreciated the services that exist. Professionals' views tended towards optimism about people's strengths and ability to adapt and make use of available services. All participants highlighted the importance of the recent developments in specialist younger people's services.

CHAPTER FOUR: DISCUSSION

4.1 Overview

The aim of this study was to explore the experience of coping with young onset dementia, from the perspective of the sufferer, partner, and the couple as a dyad. Participants described their experiences and factors affecting their ability to cope with the related life changes including beliefs about dementia, context for understanding dementia, impact of the sufferer's experiences, sense of self, relationships and support. The study also aimed to examine the experiences of professionals working in young onset dementia, their views about the coping processes used by couples, and their own ways of working.

This chapter will summarise the main findings from the qualitative investigation and review these in relation to existing literature. The strengths and limitations of this study will then be considered, as well as potential implications of the findings for clinical practice and potential areas of future research.

4.2 Interpretation of results

Semi-structured interviews were conducted with six couples, and the analysis of these interviews led to the identification of six superordinate themes. The analysis of the interviews conducted with six professionals revealed three superordinate themes. Within each of these themes, a number of master themes also emerged. The following section will discuss the themes in turn, comparing with existing literature and highlighting new insights. For clarity, the couples' and professionals' results will be discussed separately.

4.3 Couples

The six superordinate themes were related to the challenges couples faced over the trajectory of the illness, as experienced by the sufferer and the partner. Each superordinate theme encompassed a number of master themes.

4.3.1 Superordinate Theme 1: View of dementia

The theme “**View of dementia**” captures the reflections of the couple on the expectations of, and feelings about, dementia. Central to this theme was participants’ hindsight view of their “*Early symptoms*”. These were experienced with a general sense of anxiety and described mostly from the partners’ perspectives. Linked to this was a sense that “*There’s something wrong*”; both these themes were consistent with literature on early stage dementia with older and with younger people (Robinson *et al.* 2005; Svanberg *et al.* 2011). “*Finding alternative explanations*” was characterised by suspicion about the early feelings and symptoms, coupled with denial of the possibility of dementia (Robinson *et al.* 2005). The feelings of grief, loss and anger were related to the perceived untimeliness of the dementia. Early symptoms such as forgetfulness or getting lost were likely to be interpreted as being due to stress, tiredness, or illness. However, participants reported early symptoms being more varied than loss of memory (Smits *et al.* 2011). Some reported depression early on in their illness, which is a common prodromal symptom of dementia particularly in younger people (Cox & Keady, 1999). The sufferers’ “*Model of dementia*” was raised, which centred on dementia only happening ‘to older people’. This theme has been alluded to in other literature (e.g. Svanberg *et al.* 2011). Reactions of shock and distress at the eventual diagnosis were, in this study, accompanied by the partners feeling a measure of guilt.

4.3.2 Superordinate Theme 2: Living with a diagnosis

A diagnosis of dementia has a unique impact which has been widely studied; some key elements of the impact are reflected in the current study. In particular, all couples described their “**Diversity of Emotions**” experienced since diagnosis. The range of emotions included “*Fear of the future*” and a strong “*Feeling of being stigmatised*”. This supports previous findings (Husband, 2000), although the current study has brought this into focus for couples rather than individuals. Some couples also described a particular emotional consequence of dementia, namely that they had observed the sufferer’s emotional experience seemingly ‘magnified’ since the development of the dementia. It was unclear why this might be the case, and did not seem to be solely based on hypervigilance, but could be a combination of factors resulting from the effect of the dementia, the emotions described above, and possibly reduced coping abilities.

Couples also described having to deal with their now **“Unpredictable lifestyle”** since diagnosis, and having to adjust their lifestyle (Robinson *et al.* 2005). Most couples reported *“Loss of activities”* since diagnosis. Some chose to limit their activities due to fear of making a mistake in public or of what others would think of them. For some, the loss of activities was not necessarily from choice, but was linked to practical factors such as having to stop driving or feeling more tired. The theme *“Dealing with uncertainty”* raised issues from the inability to plan for the future and emphasised that a major factor in adjustment was the ability to be flexible in how they dealt with everyday occurrences. However, the theme *“Holding on to hope”* identified a tendency of sufferers and partners to interpret uncertainty, such as vagueness of a diagnosis or professionals’ language, as providing hope that ‘it may not be dementia’. A feeling of control and autonomy is seen as a strong factor in other literature, in particular regarding the cognitive control of events, where situations or events perceived as having some controllability are linked to lower appraisals of stress (Miller, 1979; Roth & Cohen, 1986). In this study, the use of uncertainty was reported as somewhat optimistic, with the resultant hope enabling them to carry on their lives with a modicum of positivity about the future.

4.3.3 Superordinate Theme 3: Effect on couple relationship

All couples found that their relationship had changed a great deal since diagnosis, which is a common finding in previous literature (e.g. Clare, 2002; Harris & Keady, 2004; Robinson *et al.* 2005). Couples reported that **“Change in roles”** and shifts in **“Couple identity”** were particular issues that they have negotiated, explicitly or implicitly. The extent to which couples felt comfortable with these changes affected the balance of **“Control and responsibility”** within the relationship and home life. The gender roles described by participants, and their ease of adjustment to the caring role related to their gender, was similar to that of previous research findings. Most of the couples reported that they had had ‘traditional roles’ prior to the diagnosis of dementia, and that adjustment had been needed especially by the male partners (Dalley, 1996; Graham, 1993). One male partner admitted that he found this adjustment difficult, and another felt concerned about his adjustment in the future as the dementia progressed.

As reported in previous literature, some of the couples reported particular stress related to employment and financial worries, as a consequence of the sufferer having to stop work abruptly (Luscombe *et al.* 1998). However, this appeared to be freely discussed by the couples in this study, in contrast to previous reports that sufferers are unaware or that carers actively withhold their worries from their partners (Beattie *et al.*, 2004). This highlights the importance of including the partner, where possible, in assessment and interventions for dementia. Some couples mentioned hypervigilance for mistakes, leading to anxiety for both and overprotection by the partner. This has been suggested in previous literature (Jones, 1995). However, the couples here seemed to be very aware of this tendency.

More positively, the findings of this study support previous literature indicating that some couples find that their relationship improves following a diagnosis of dementia. For some couples, the diagnosis itself provides some clarity and focus, often following a long period of uncertainty, stress and worry (SCIE, 2012), and provides a challenge to deal with together (Farran, 1997).

4.3.4 Superordinate Theme 4: Relationships with others

Couples found that the dementia had also had a major effect on their relationships with others, including family and friends. In particular, couples felt that others' "*Lack of awareness*" had mixed effects, in that it could mean others did not expect them to show typical symptoms of a dementia, but also that sufferers were somewhat excluded from conversations. One couple had become uncomfortably aware of other people trying to 'test them out', perhaps to demonstrate their deficits.

Previous literature has noted that negative stereotypes or perceptions of dementia can cause people to keep their diagnosis from others, leading to others withdrawing social support (Clare, 2002; Husband, 2000). However, the theme of '*Isolation*' in this study was explained by others' reluctance to engage due to fear about dementia, or a lack of understanding. For many, the changed relationships meant that friends and family lost contact. This left couples, particularly the sufferers, feeling hurt and abandoned. This has been described in previous literature that has focused on older couples (Dempsey & Baago, 1998; Robinson *et al.* 2005). Isolation from services was also reported. Couples often felt that they did not belong in older people's services and had the prevailing feeling that dementia services were fundamentally for

older people. Even when services made efforts to adapt for younger people, couples' prevailing feelings were of uncertainty and seclusion (Williams *et al.* 2001; Harris, 2006).

4.3.5 Superordinate Theme 5: Coping strategies

All couples described personal and relational coping strategies which they used to help adjust to the life changes associated with a dementia. The strategies described supported the previous literature on coping in dementia (Kneebone & Martin, 2003). Of prime importance were strategies focused on the couples' "**Social identity**". Some couples described that the isolation from their usual social groups led them towards making new friends as a couple through peer support groups and thus "*Developing compensatory relationships*". Within these new relationships, they found that they were able to accept the dementia as it became part of their lives. "*Finding a group identity*" alongside other couples in similar situations, and the engendering of new social roles, was reported as being very helpful for the couples in this study.

Couples also employed a number of common "**Practical strategies**", which mainly centred around "*Keeping busy*" and "*Distraction*", particularly when the partner noticed the sufferer feeling anxious or unwell. These strategies helped the sufferer to avoid getting caught up in, or becoming anxious about, their symptoms. Such strategies were intended to positively influence the sufferer's self-esteem (Clare, 2002; Kneebone & Martin, 2003). "**Emotional strategies**" used included the partner feeling responsible for "*Building confidence / self-esteem*" of the sufferer. As couples gradually acknowledged the dementia as being real and permanent, the theme of "*Acceptance*" also described the impact of this acknowledgement on the participants. Accepting the dementia as real impacted on self-identity, but also allowed couples to make sense of the associated limitations and losses (Clare, 2002). Some couples also employed "*Positive thinking*", mainly around the feeling that they had to 'make the best of it' and carry on with their lives as far as possible, without dwelling on their losses. Some examples described by participants included a sense of increased spontaneity in terms of engaging with activities and 'living for today'.

However, some couples also reported the use of "*Avoidance*" in thinking about the dementia. It is suggested in previous literature that avoidance may have a positive impact, in mediating when and how people engage with more detailed information about dementia and likely futures (Clare, 2002). 'Avoidance' in this study did not

explicitly link with poorer coping, however one of the theoretical models utilised in the current study suggests that prolonged avoidance is likely to lead to poorer emotional outcomes (Lazarus & Folkman, 1984).

4.3.6 Superordinate Theme 6: Reflections on treatment and services

Couples' accounts of the support process were characterised by a sense of bewilderment and struggle, captured by the theme of **"Uncertainty"**. Themes were also underpinned by a general sense of unfairness. Frustration was often directed at the healthcare system, which was sometimes seen as not acting quickly enough and not being able to solve the problem. Most couples had not experienced serious health problems prior to the development of dementia, and thus had not come into contact with healthcare systems before. Some couples seemed to have had high expectations of 'being fixed' and of professionals providing a definitive answer for them. The stress appraisal model postulated by Lazarus & Folkman (1984) is reflected by this theme, in terms of the importance of a sense of control. For example, being able to personally achieve a sense of control by taking a tablet for an illness may reduce the stress of the experiences of an otherwise uncontrollable situation (Lazarus & Folkman, 1984; Miller, 1979).

Most couples felt that the **"Need for increased awareness"** about the fact that younger people can develop dementia left them feeling marginalised by society. This has been reflected in previous studies and appears to be a strong prevailing view of younger people with dementia (Clare, 2002; Kneebone & Martin, 2003).

The theme **"Timeliness of post diagnosis support"** revealed uncertainty and difficulty as couples attempted to negotiate new information and new systems, and to learn what they could expect from services. Although views were mixed as to whether they would have wanted earlier support, the general feeling was that couples did not want to, or did not know how to, ask for more support. Information provision and an individually paced approach were raised by couples as being desirable in terms of immediate input from services. Previous studies have highlighted the need for services to provide interventions around the time of receiving the diagnosis (Moniz-Cook & Woods, 1997) and have recommended that couples are offered more emotional support and practical help after a diagnosis (Robinson *et al.* 2005). Further

recommendations about support have included the use of a multi-component intervention such as group or individual work (Bourgeois *et al.* 1996; Ingebretsen & Solem, 1998).

None of the couples in the current study had experienced inpatient admissions since their diagnosis, and therefore did not reflect on this issue.

4.4 Professionals

Three superordinate themes emerged from the professionals' interviews, each containing a number of master themes, relating to their experiences of working with sufferers and partners of those with young onset dementia.

4.4.1 Superordinate Theme 1: Coping strategies of sufferers and partners

Some professionals reflected on the tendency of couples for “**Utilising uncertainty**”, particularly regarding diagnosis or prognosis, and used this in “*Holding on to hope*”. This tendency has been described in previous literature (Clare, 2002), and seemed analogous to that described by the couples in this study. However, the process by which sufferers and partners take advantage of uncertainty to focus on hope, to help them to cope, has been more explicitly described in this study by both couples and professionals. In particular, the uncertainty of the early symptoms, and of the professionals, is coupled with the use of technology to find out information that might help them to retain hope for the future. This tendency was described as having the potential to be positive or negative, depending on the intention of the sufferer or partner to use selected information to support their denial or acceptance of the dementia. Linked to this were mixed views about whether couples were “*Predicting the future*”, mainly by comparison with others. Comparing with others is a common finding in previous literature on coping with dementia (e.g. Clare, 2002), but it seems to be dependent on the individual or couple concerned as to whether the comparisons are interpreted as positive or negative.

“**Emotional strategies**” used by couples were felt to be varied. “*Searching for meaning*” included couples finding alternative explanations for their early symptoms. “*Comparing with others*” was a process by which couples try to second-guess their position within the illness trajectory and to see this in a positive or negative light,

whilst “*Maintaining identity*” was seen to be important in retaining a sense of self-esteem and continuity amidst the uncertainty. Similarly to previous literature (Clare, 2002), “*Holding on to control*” was a theme in this study, but was largely represented here as a tendency amongst younger people to state future suicidal ideation as a way of retaining a sense of control. A similar theme was raised by couples in this study.

“**Practical strategies**” centred mainly on the sufferer “*Keeping going*” with their usual activities as much as possible. This was seen as another way of maintaining a sense of normality and control. “*Talking to others*” was discussed mainly in the context of peer contact, and was felt to assist in reducing caregiver burden as well as normalising the sufferer’s experiences (Weuve *et al.* 2000). Perhaps surprisingly, professionals did not raise the role of practical strategies usually advised to couples, such as memory strategies or house adaptations (Alzheimer’s Society, 2002). It was unclear whether these were presumed to already form part of the couples’ adjustment and adaptations, and therefore not considered to be an important issue to raise in the context of the current study.

4.4.2 Superordinate Theme 2: Factors affecting coping by sufferers and partners

Respondents identified a number of factors that have affected the ability and willingness of couples to adjust following a diagnosis of dementia. “**Individual factors**” related to the sufferer’s personal resources and emotional styles. Within this was the theme of “*Emotional reactions*”, which encompassed shock, denial, frustration, and particularly fear. The “*Impact of the dementia*” was described as mainly limiting the coping resources of the sufferer. It was noted that coping strategies from prior events cannot easily be drawn upon in these circumstances, suggesting that a young onset dementia poses unprecedented challenges. Within the theme of “*Hopes and expectations*”, professionals described encountering the high expectations of sufferers, partners and families. Professionals felt pressured at times to provide a cure, or definitive answers about the future, and felt that a big part of their work was to encourage their clients to adjust their expectations.

“Relational factors” centred around the *“Impact of Role changes”* for couples and the resultant *“Effect on couple relationship”*. Similarly to the couples, professionals reflected that the role changes usually meant that the partner overprotected the sufferer, perhaps leading to a loss of skills. This reflects previous literature in dementia (Freyne *et al.* 1999) although this may seem to be a particular issue for younger people, given the more rapid rate of deterioration (Clare, 2002; Harvey, 1998). A significant issue raised was the effect on the marital relationship, in that the demands of caring, as well as the effect of the dementia, may lead to a change in sexual feelings between the couple. This has been raised in a very limited number of previous studies (e.g. Harris, 2009; Davies *et al.* 1998) which focused on older people with early stage Alzheimer’s disease. Another key aspect was the sense that partners experience ambiguous grief about the unknown future of the sufferer (Boss *et al.* 2004), where the partner has to live with the paradox of simultaneous presence and absence of the person with dementia (Boss, 2007). This aspect has been explored in caregivers of older people with dementia (Sanders *et al.* 2008), but has not yet been investigated in younger couples.

“Systemic factors” related to the wider family, friends and community networks of the couple. In particular, it emerged that young onset dementia has an *“Impact on multiple generations”*, in a way that is perhaps unique to the condition. Professionals expressed concerns about the effect on children as well as the parents and the extended family of someone with a young onset dementia, and this seemed to relate to the symptoms associated with the dementia and the developmental stage of the families involved (Allen *et al.* 2009; Kurz *et al.* 2008). There are similar findings in some literature related to terminal illnesses in younger people (e.g. Chang & Johnson, 2012), which can also be applied to working with dementia. Professionals, similarly to the couples in this study, also discussed the sense of *“Isolation”* experienced by couples in terms of withdrawal of others and a sense of not fitting in to services. The prevailing *“Societal values”* also arose as a factor influencing adjustment and coping processes. Professionals also reflected on the multifactorial impact of dementia on society, and the need for sufferers to relinquish societal values such as career or achievement when affected by a dementia.

4.4.3 Superordinate Theme 3: Contextual factors for professionals

There was a strong observation that working with younger people with dementia can have an intense emotional and personal effect on professionals. Within the theme “**Challenges for professionals**”, the participants described the “*Identification with service users*” as almost inevitable, affecting their perception of, and emotional reaction to, the people they worked with. Especially poignant were issues related to a sufferer of a similar age or life stage. Notably, professionals described feeling a sense of responsibility for trying to ensure a successful outcome for the sufferer, perhaps greater than they usually would. Professionals’ feelings about “*Dealing with uncertainty*” often resulted in them feeling uncertain themselves about how best to work effectively given the lack of answers. In terms of service limitations, some described a feeling of “*Professional impotence*”, where they felt there was nothing useful they could do. To manage these fluctuating feelings, most professionals described a number of “*Coping strategies*” that they employed, including the use of varied modes of supervision and finding a good work life balance.

A number of “**Service challenges**” were identified by professionals. Within the theme of “*Diagnosis issues*”, professionals described the sometimes tense balance between the necessity for thorough but prolonged diagnosis of young onset dementia, and the possibility of misdiagnosis (Davies & Lerner, 2009). Some professionals raised the issue of younger sufferers expressing thoughts about ending their lives at a certain point in their illness. An increased risk of suicidal ideation is thought, in the existing literature, to relate to a hasty dementia diagnosis, or in situations in which the couple has not been sufficiently prepared for diagnosis (Draper, Pesiah *et al.* 2010). However, within the current study, such expressions by sufferers were described as a further strategy for holding on to control – a process that has not been previously addressed in the literature.

Professionals raised the issue of “*Service dilemmas*”, with a view of the whole course of the person’s dementia. The discussions reflected the nature of current service setups, as it is difficult to meet longer term physical and safety needs of a younger person with dementia (Rose *et al.* 2010). This is complicated by the higher likelihood of a younger person needing hospital admission (Draper, Gibson *et al.* 2010), and professionals incorporated into the discussions the high likelihood that many sufferers would need inpatient care at some point in the future. The gap in inpatient service was identified as a concern in the context of current, age-dependent inpatient

wards. Younger people with dementia are more likely to have good physical health, but may display higher levels of frustration and aggression, and this led to concerns being voiced about potential risks to older people of such a patient being placed on an older people's dementia ward. However, it has been suggested that inpatient wards should be needs-based and not necessarily age-based (Alzheimer's Society, 2002; Armstrong, 2003).

Similarly to the couples' views, the "*Societal view of dementia*" described the problematic lack of awareness within the general population about dementia affecting younger people. However, all professionals described their enthusiasm for their work, and positivity about ways of "**Supporting coping processes**" with sufferers and partners. Some of the ways they had considered doing this included the provision of "*Information support*", and ideas for approaches to this, such as monitoring language used. "*Supporting independence*" of the sufferer included considerations such as identifying strengths, respecting people where they are, and confidence building. It was felt to be important to balance attitudes of protection and independence, and professionals also stressed the importance of maintaining flexibility in dealing with unpredictable, uncertain, fluctuating abilities. Person-centred care was also said to be key, to take account of the variety of needs, circumstances, beliefs and opinions of people with young onset dementia.

The professionals' interviews add to the sparse literature on staff perspectives of working with younger people with dementia, and indicate an emerging change of paradigm in how people use dementia services, and how medical professionals work with people with dementia.

4.5 Comparison of the views of participant groups

The current study did not set out to compare the views of the couples participating with the professionals. However, it is interesting to note that broadly their views seemed to coincide. In particular, there was a general sense that both groups felt similarly on a number of points:

Both groups of participants recognised that living with the uncertainty of dementia, throughout its stages, has a major impact which needs to be explicitly acknowledged. Both groups raised the issue of the effect of the uncertain nature of the condition as sometimes being useful in helping to provide a positive slant, which seemed to be an

important theme in helping those affected to cope by retaining a realistic level of hope about the future.

Both groups of participants acknowledged the change in relationship roles and the impact this can have on the couples. Couples and professionals both felt that peer support was key in re-negotiating future plans as well as in lifting the mood of the sufferer and partner on a day to day basis by providing social contact and deriving pleasure and meaning. However, both groups also expressed concern about the high risk of social isolation associated with dementia, and the experience of isolation was reported by both groups as having a negative impact on couples' ability to cope and on their emotional wellbeing.

There were, however, a small number of aspects on which there were slightly different views between couples and professionals.

Both groups described a number of emotional coping strategies, but couples and professionals differed slightly on their views of what was most effective. Couples felt that building confidence and acceptance was important, whilst professionals thought that it was more important for couples to seek meaning and control. In addition, couple participants felt that coping was focused on their relationship and was strongly impacted upon by a certain lack of awareness of others in society; whereas professionals felt that coping was affected mainly by individual factors, and placed less emphasis on societal factors. In terms of practical strategies, couples felt that keeping busy and distraction were primary coping strategies; although professionals largely agreed with this, they also felt that sometimes the sufferer needed more support to reduce their potential risks.

Professionals explicitly discussed the impact of young onset dementia on multiple generations, whereas the couples alluded to this in less distinct ways. Couples tended to refer to the impact on their family mainly within the context of siblings, and others within their generational groups, seemingly avoiding contact with the couple as the dementia progressed.

In terms of support provision, couples felt that although the overall support provided was good and timely, most felt that they would have liked more input immediately post diagnosis. Professionals however felt that couples 'needed more space' before services offered support. This would seem to be a key difference which could potentially affect the services that sufferers and partners receive, and when.

4.6 Implications of findings

The results of the current study indicated a number of implications for clinical practice and for the role of professionals in working with young onset dementia, at the level of the individual, couple or family, and for service provision.

4.6.1 Clinical implications

A key finding of this study was that the impact of young onset dementia poses unprecedented challenges to the lives of sufferers and partners, and that this is very different to challenges imposed by a dementia in older age or by other types of illnesses or health conditions. Although coping strategies will vary between individuals, this study provides evidence for the effectiveness of certain strategies for maintaining a good quality of life, such as encouraging independence and activities to rebuild confidence, self-esteem, and the use of acceptance.

The need for retaining a sense of control was described as a key component for sufferers and partners, and was also recognised by professionals as being an important factor in coping. Longer term, tools such as Advance Directives can enable the sufferer to plan for their future, and help them to maintain a feeling of control over their lives in the face of dementia (Robinson *et al.* 2010). However, this study also raised a sensitive issue which may need to be considered in future, namely that professionals may need to acknowledge that sufferers' feelings about their future might include thoughts about ending their lives at a certain point in their illness. Professionals may therefore need to balance considerations of risk with an awareness of the emotive nature of such discussions for all concerned.

The benefits of peer support for this group are clear in terms of increased self-esteem resulting from group identity. However, it was acknowledged that some sufferers and partners may not feel able to engage in groups or to accept the new identity, and individualised methods of support should be considered where possible.

In terms of individual interventions, at present the psychological therapies designed for younger people with dementia have not yet been widely studied. Reminiscence therapy, for example, has been researched in older people and found to have a good effect (Woods *et al.* 2009); in the current study, reminiscence therapy was described by professionals as being used to good effect in current services for younger people, using age and cohort appropriate considerations. The potential for other therapies in

working with younger people with dementia could be further explored, such as Third Wave cognitive therapies which have been shown to have good effect for chronic life-limiting conditions (Shennan *et al.* 2010; Speca *et al.* 2000; Teasdale & Bartley, 2011).

Partners in this study stated the importance of including partners/carers as fully as possible in assessment and interventions, and account taken of the likely and stressful changes in their couple relationship and increased demands on the partner. Thus, services could consider ways to offer support for likely emotional reactions of the partner, such as grief and guilt, as they experience the transition into the role of 'carer', and to encourage them to monitor their own health and wellbeing.

There was some ambivalence expressed by the couples between wanting intervention and resisting help, particularly where this might entail psychological help. This may be partly due to their perception of the social stigma associated with dementia, leading to feeling that they had to 'cope by themselves'. Interventions therefore need to be offered in a way that allows sufferers and partners to feel able to accept help without experiencing shame. In addition, unresolved psychological difficulties, such as past trauma, or difficulties in psychological flexibility, may adversely affect coping outcomes and may need to be addressed. It may also be important to recognise that coping is essentially a continuum (Lazarus & Folkman, 1984; Clare, 2002) and may fluctuate throughout the course of the dementia. Providing information and reassurance about this likely process may help partners in particular.

With regard to information provision, clinicians need to maintain an awareness of uncertainty in language used and the likely impact. It may be helpful to conceptualise the process of information provision as an ongoing collaboration between clinician, sufferer and partner, rather than a one off conversation about diagnosis. Clear information about the structure of, and relationship between, existing agencies providing support, should also be included in the process. In addition, this study recognised the willingness and ability of younger people to use technology to seek information; this could also be utilised, perhaps by providing or facilitating access to relevant online information.

One issue raised was that psychosexual factors form a major aspect of the way in which the couple relationship is affected by dementia. This may be something that couples are not comfortable raising with their care providers, but nonetheless may present a problem, affecting self-esteem, communication and life satisfaction. Professionals within services for younger onset dementia should consider the need to facilitate the addressing of such issues, by offering opportunities for sufferers and partners to talk about changed aspects of their relationship.

For staff, the unique challenges of working with the high levels of uncertainty inherent in young onset dementia may mean staff will be at particular risk of burnout (Ilhan *et al.* 2008; Prosser *et al.* 1996). It was clear from the results of this study that there is a need to ensure that professionals are well supported with a variety of modalities, including structured clinical supervision, accessible professional and emotional support, ad-hoc consultation and peer contact. Particular acknowledgement needs to be given to the personal impact of working with younger people with dementia, and support should include encouraging professionals to maintain a good work-life balance.

4.6.2 Service implications

Specialist services for young onset dementia are still very new, however the results of this study suggest some potential areas of consideration for their development.

With regard to timing of post diagnosis support, this study found that it would be beneficial to maintain flexibility in interventions where possible, according to the needs of the sufferer and family. Information provision and an individually paced approach were said to be needed with regard to immediate input from services. It has been suggested previously that interventions could be offered around the time of receiving the diagnosis (Moniz-Cook & Woods, 1997) and this was indeed reflected in the results of this study. Couples felt that they needed a mixture of emotional support and practical help directly following a diagnosis, and this could be achieved via multiple modalities including group and individual work, as suggested by previous studies (Bourgeois *et al.* 1996; Ingebretsen & Solem, 1998; Robinson *et al.* 2010). Services should also maintain an awareness of the likely impact on relationships of a dementia, and this may have training implications in terms of staff working with younger people with dementia living in the community.

For sufferers requiring inpatient admission, services need to carefully consider where their needs are best met. There were mixed views in this study as to whether younger people are best admitted to wards catering for dementia, usually with people much older than themselves, or on a working age adult mental health ward. The placement decision may be best influenced by the person's level of cognitive and adaptive functioning at the time of admission. Since services for younger people are still at an early stage of development, the goodness of fit of existing inpatient provision will need to be monitored as services develop. An example of a potential tool that could be used to continue to monitor this issue is Dementia Care Mapping (van de Ven *et al.* 2012). Dementia Care Mapping has been used in previous research to monitor the quality of life of people with dementia in nursing and residential care homes, and to make suggestions for related improvements to staff training (Ballard *et al.* 2005). In addition, tools such as the Person-Centred Climate Questionnaire may have applicable properties in a hospital setting and include the view of the patient (Edvardsson & Innes, 2010). Developing person-centred pathways of dementia care requires a systemic approach where services are able to maximise intrapersonal, interpersonal, and community resources. However, moves towards person-centred models of dementia care may be fraught with challenges from historically medically-oriented, and risk-averse, treatment models. These potential anxieties need to be addressed through highlighting the different roles of multi-disciplinary professionals within the treatment system, to facilitate sustainable care.

In terms of the societal issues discussed in this study, a notable factor was the feeling of a general lack of awareness of dementia amongst the population, and particularly the fact that it affects younger people. There would seem to be a strong need for the promotion of positive awareness amongst the public and primary care services. Services should also maintain awareness of the high risk of social isolation as a consequence of having dementia, and the potentially negative impact on sufferers and families.

Most couple participants indicated feeling that they had received good support from the memory clinics, and suggested that they, as well as third sector agencies, may have a key role in promoting constructive views of dementia as not just a disease of old age. Although there are identified and ongoing difficulties in arriving at a diagnosis, Memory Clinics will continue to be crucial in monitoring younger people with dementia or dementia-like conditions (Kopelman & Crawford, 1996).

4.6.3 The role of clinical psychology

Clinical psychology can play a central role in working to ensure that the needs of younger people with dementia are better met. The current study has highlighted the importance of considering multiple facets of clinical practice to improve the way that services are delivered, particularly with regards to addressing psychosocial needs. Clinical psychologists have a unique skill set which well places them to exert an influence at multiple levels.

Delivering interventions aimed at improving psychological outcomes for sufferer and partner could be a key role alongside assessment within a memory clinic. Some potential examples of this could include: improving access to services for sufferers and carers; addressing ambivalence in help seeking; involvement in longer term care planning when needs change as the dementia progresses; addressing psychological difficulties in sufferers and carers; incorporating post-diagnosis support; developing links with third sector and other agencies; and the development of peer support networks.

Consultation and supervision of other professionals is a key role of a clinical psychologist within a multi-disciplinary team, and can help a team to develop a cohesive approach as well as provide much needed support frameworks for staff. The leadership, teaching, training and consultancy skills of clinical psychologists can be utilised to enhance others' understanding of young onset dementia, to encourage well-evidenced changes in service delivery. Clinical psychologists could therefore utilise their skills to increase awareness about young onset dementia and its implications. This study showed the importance of this task for the public, GP's and health professionals at all levels.

Recent public debates about the quality of dementia care have highlighted the gap between evidence-based guidelines and clinical practice (Alzheimer's Society, 2012). To continue enhancing understanding of the growing area and impact of young onset dementia, longer-term intervention outcomes need to be evaluated. Clinical psychologists can take a lead role in implementing such evaluations.

4.7 Critical appraisal of the current study

Methodological and design limitations and strengths will be discussed below.

4.7.1 Sample

The study employed a small sample of two groups of participants: six couples (each comprising one sufferer and one partner), and six professionals. The sample size fits with IPA recommendations, which suggest that smaller sample sizes facilitate investigation of the richness of personal and shared experiences (Crouch & Mackenzie, 2006; Elliot *et al.* 1999; Smith *et al.* 2009) and a sample size of 5 or 6 has been suggested as an adequate figure for studies using IPA methodology (Smith & Osborn, 2003). In addition, several qualitative studies in dementia literature have employed similar sample sizes (e.g. Clare, 2002; Robinson *et al.* 2005). The two groups of participants would conform to these recommendations and precedents.

A number of characteristics of the couples in this study should be borne in mind in terms of generalising to the population of younger people with dementia (Barker *et al.* 2002). It was not possible to balance the gender in terms of the sufferer and partner. Four participants with dementia were female and two were male. This may have had some implications for this study in terms of the attitudes and feelings of the participants, in that most of the partners were male and the move towards the 'carer' role perhaps required more explicit consideration (Dalley, 1996; Graham, 1993).

Participants were not selected for specific diagnoses, but 5 of the 6 sufferers had a probable diagnosis of early onset Alzheimer's disease and were taking anti-dementia medication. This may have implications for future research, since many younger sufferers are likely to have a rarer type of dementia such as frontotemporal dementia. The sufferers were also all functioning at similar cognitive levels at the time of interviews. In addition, the couples were all in their 50s or early 60s at the time of diagnosis, were in a long term marriage or stable heterosexual relationship, with children in their 20s and 30s. It is likely that many people with young onset dementia will have much younger children (Alzheimer's Society, 2002), which would create a very different set of challenges for the couple. All couples were from the South Wales area and were white, British, and of similar socioeconomic status. This meant that the study explored only one type of cultural perspective.

Of the professional participants, 3 were female and 3 male, all were white British, and all were employed by the NHS. They varied in degrees of qualification and the length of experience in the field. This focus was therefore on 'professionals working in young onset dementia', rather than on any specific profession. The professional

participants also had varying levels of contact with service users – some were front line staff, and some had managerial responsibilities as well as clinical ones. This allowed a variety of viewpoints to be represented, and reflects the typical distribution of a multi-disciplinary service. Therefore, the findings may provide a valuable basis for further investigation into the experience of staff groups.

Qualitative research generally does not claim to represent the population it is examining (Harris & Keady, 2004). The purpose of this study was to present a detailed and diverse picture of a previously reported phenomenon and to use the narratives to form a better understanding of the issues faced by younger people with dementia and their partners (Harris & Keady, 2004).

4.7.2 Recruitment

Both couples and professional participants were self-selecting from approaches made by the clinic. This recruitment strategy may have introduced a bias into the results. It was not known who did not elect to participate, and their reasons. Some people with young onset dementia and their partners may have had difficulties talking about their losses (Robinson *et al.* 2005). Potential couple participants may have been selected by the memory clinic according to their coping ability or success.

In terms of the couples' interviews, although it was decided that the study would focus on couples together to explore the dynamics between the two, it is acknowledged that this may have introduced certain limitations. For example, spouses may have been careful to monitor their responses to avoid upsetting their partner (Robinson *et al.* 2005). The discussions also featured retrospective accounts of the situation as well as current situations, and this should be borne in mind in looking at the results.

4.7.3 Data collection and analysis

The aim of the study was to gather data about the experiences of coping with young onset dementia, with a focus on the relationship between the sufferer and the partner. The interview schedules used for participants consisted of questions that were developed with this broad aim in mind. The questions included in the interview schedule were open ended, and were asked in the context of stories recounted to

enable dementia sufferers, with cognitive difficulties, to engage more easily. The researcher remained mindful throughout the interviews to use the schedule flexibly.

The researcher considered, together with the academic supervisor and other clinical psychologists familiar with research in the field of dementia, the different ways in which the data could have been analysed and themes generated in accordance with the methodology. A different approach would have been to cluster the 'sufferer' and 'partner' themes separately, rather than as 'couples' – however it was felt that as the focus was on the couple dyad, this would have lost much of the detail of the relationship factors. The researcher is aware that a different approach to the analysis, or utilising a different qualitative methodology, might have yielded different results, but the researcher is satisfied that the analysis adopted in this study was appropriate.

A strength of this methodology was that it conformed to the criteria set out by Elliott *et al.* (1999) for quality in qualitative research. However, a common criticism of qualitative methodology is that self-report has potential validity problems – data are personal and idiosyncratic, and it must be acknowledged that respondents' words may not have accurately reflected the truth, but rather the 'truth' as they wished it to be heard (Barker *et al.* 2002). The possibility of the researcher imposing a perspective and research agenda upon participants is also an inherent risk of qualitative research, and this risk may be increased when participants have cognitive difficulties (Cox & Keady, 1999; Wilkinson, 2002).

In terms of the specific analytic techniques used, it is acknowledged that different researchers' emotional responses may lead to different interpretations (Kincheloe & Maclaren, 2002). This study was conducted with awareness of this potential, and monitored by the use of supervision and the reflective diary.

4.7.4 Conducting the study

Potential ethical issues with this study were considered carefully from the outset, particularly in terms of interviewing people with cognitive impairment. It was noted that the clinical team and the researcher were very aware of the possibility of cognitive changes, of the importance of gaining fully informed consent from the participants, and for the researcher to monitor ethical issues which might have arisen

during the interviews. The researcher visited 5 out of the 6 couples at home alone, and although lone worker policy was complied with, the researcher was aware that this could have meant that there was a small risk to her. This approach, however, allowed participants to feel comfortable and relaxed, and to have some control over the setting of the interview. Such elements were felt to be beneficial to participants' ability to express themselves freely, and thus encouraging of their full participation. The robust back up procedures set up at the beginning of the study (outlined in Chapter 2) were also felt to be protective, and indeed no issues arose. During one couple interview, the researcher found some difficulties in maintaining the couples' attention to the semi structured questions, and was careful to maintain a balance between gentle repetition of the questions with awareness of the potential for leading the interview. Advice was sought from a supervisor following the interview, and the experience was felt by both researcher and supervisor to reflect the challenges of conducting research with this population and should not preclude the involvement of people with dementia in direct research (Cox & Keady, 1999; Wilkinson, 2002).

4.8 Future research

Much research into dementia has focused on medical aetiology and treatments. Through focusing attention on younger people and on the psychological impact of dementia on the person, family and services, this study suggests several potential areas for further investigation.

The findings did not explicitly address predictive risk factors for poor coping in couples, and this could be investigated further with the aim of gaining information to help clinicians identify those who are more likely to have difficulty in coping. It was also unclear from this study whether the ability to adjust to young onset dementia was related to the individual's perception of their own physical and mental health, which could be further explored as a potential factor affecting coping.

Most research in dementia is focused on the more difficult aspects such as loss, grief, and behavioural difficulties. However, some positive aspects of dementia were identified in this study, such as, for some couples, a strengthening of the relationship (SCIE, 2012). Positive consequences of care for carers (Haley *et al.* 2009) have been previously investigated and these factors could be explored further for younger people, perhaps linking to social policy and third sector aims to promote the strengths and talents of people with dementia.

The use of a different methodology such as longitudinal research could explore sufferers', partners' and professionals' experiences at the time of diagnosis and at intervals following diagnosis, perhaps by conducting interviews at different time points. This would provide a greater understanding of the process over time, since the current study relied on a retrospective account. Such a study would, however, need to consider the impact of potential difficulties with individuals' capacity to consent at later stages of dementia. Alternatively, a quantitative design could be employed, perhaps using standardised questionnaires or survey methodology to measure aspects of mood related to coping styles at different points in the journey. This could also capture the experiences of a wider variety of participants. Some measurement of understanding and knowledge of dementia of family members may also prove useful, since this study indicated that more distant family members may have limited awareness leading to further distancing from the sufferer (Wilson, 1989).

The current study did not separate out professional groups, however further research could explore the views of different professions. The perspectives of those working in third sector agencies could also be usefully explored. The views of front line staff on dementia or working age adult mental health wards could be sought, regarding the admission of younger people with dementia to inpatient wards. The current study only explored the couples' timeframe since the development of the dementia, and the couples in this study had not experienced inpatient admissions. Future research could seek the views of families of younger people with dementia who had been admitted to inpatient wards, to explore their perspectives on the types of wards that may best suit the needs of younger people with dementia.

4.9 Conclusions

The aim of this study was to explore qualitatively the perspectives of couples and professionals separately about the challenges resulting from young onset dementia. It is hoped that this study will add to the understanding of how the perspectives of both sufferer and partner interact, and the impact of the perspective of professionals on treatment and support.

Although several studies have explored the coping experiences of couples with dementia, the current study appears to be the first to explore this in younger couples

and to include the perspective of professionals. A qualitative design was employed in order to convey the richness and complexity of the participants' experiences. Several factors were identified that may be particular to the circumstances of younger couples and professionals working in young onset dementia, in particular supporting some elements of the model (Robinson *et al.* 2005) discussed in Chapter One, as applied to younger couples. There was also evidence to support the model of coping with dementia (Clare, 2002) for younger people, and this highlights the relevance of additional factors such as societal prejudice and the use of technology.

It is hoped, therefore, that the current study demonstrates the importance of including the views of sufferers and partners, and conveys the diversity of experiences of couples in which one person has young onset dementia. It is also hoped that the potential influence of the views of professionals on the service users' experiences will be recognised as a major factor in working clinically with this population, as well as the value of the professionals' experiences of supporting younger people with dementia.

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Appendix 1

Systematic Literature Review search strategy

Appendix 1: Systematic Literature Review search strategy

The following table outlines the searches carried out as part of the literature review.

Details of the search strategy can be found in Section 1.4.

Search Term 1	Search Term 2	Search Term 3	Hits	Number of relevant articles after limiting searches
Dementia	Coping*		3,487	32
		Young onset	357	14
		Early onset	94	62
		Working age	13	n/a
		Couples	227	11
		Young couples	8	n/a
	Adjustment*		4,882	1,111
		Young onset	18	n/a
		Early onset	132	39
		Working age	12	n/a
		Couples	129	35
		Young couples	3	n/a
	Diagnosis*		2,161	280
		Young onset	178	11
		Early onset	64	37
		Working age	27	n/a
		Couples	224	19
		Young couples	3	n/a
Dementia	Couples*		524	9
		Young	159	7
		Young onset	1	n/a
		Early onset	26	n/a
		Working age	2	n/a
	Memory Team* / Clinic*		1,887	6
		Young	98	66

Appendix 2

Summary table of selected literature review

Summary table of selected literature review

Study	Country	Design	Sample	Ages	Diagnosis	Key results
Robinson, L, Clare, L., & Evans, K. (2005)	UK	Qualitative interviews - IPA	9 Married couples	73 – 85	Probable AD and VD	10 themes – higher order - Not quite the same person, tell me what actually is wrong and 'Everything's changed, we have to go from there'
Harris, P.B., & Keady, J. (2004)	US and UK	Qualitative – face to face interviews, focus groups and online interviews	YPWD in US (23); families of YPWD in UK (15)	<65	AD, FTD, Huntingdons	8 themes: (1) difficulties in obtaining a diagnosis; (2) issues of selfhood and self-esteem; (3) changing relationships within the family structure; (4) awareness of changes in self; (5) work and retirement/financial issues; (6) feelings of extreme social isolation and exclusion; (7) "off-time" dependency; and (8) lack of meaningful occupation.
Ingebretson, R. & Solem, P.E. (1998)	Sweden	Qualitative interviews	28 couples	60 – 87	"Dementia" (unspecified)	Patterns of attachment behaviour seen in changing couple relationships – Compulsive caregiving, anxious attachment, compulsive self sufficiency, secure attachment
Seiffer, A., Clare, L., & Harvey, R. (2005)	UK	Cross-sectional correlational – self report and informant report questionnaire	49 individuals and their partners	54 – 86	Non-frontal progressive cortical dementia	Negative attitudes towards emotional expression related to avoiding coping in managing the threat of dementia. Relationship between conscientiousness and unawareness.

Study	Country	Design	Sample	Ages	Diagnosis	Key results
Clare, L. (2002)	UK	2 qualitative interviews - IPA	12	57-83	Alzheimer's disease	Model forming a continuum, running from self-protective to integrative responding,
Aminzadeh, F., Byszewski, A., Molnar, F.J., & Eisner, M. (2007)	Canada	Audio tapes of diagnosis sessions, interviews, focus groups	30 patient/caregiver dyads	65 – 85	Probable AD and VD	Denial / lack of insight; grief reaction; positive coping responses
Kurz, A., Schulz, M., Reed, P., Wortmann, M., Rodrigo, J., von Lutzau Hohlbein, H., & Grossberg, G. (2008)	Europe, Brazil, N America	Telephone interviews	502 PWD and 614 carers	PWD mean age 73; carers mean age 48	Alzheimer's disease	Important to PWD to have medication that controls symptoms, feeling safe & supported, ability to enjoy life. Important to carers to have information about AD, easy regimen of medication.
Svanberg E., Spector A., & Stott, J. (2011).	Various	Literature review	26 studies, chapters or reports	Various	Various	Negative impact of young onset dementia on individual, family, carer, children. Diagnostic difficulties.

Appendix 3

Extracts from Reflective Diary

Extracts from Research Diary

December 2011

Received another set of participant reply forms! Exciting, as I had been worried about getting any more participants. But I can't help but feel a bit dejected about the project – feeling as if I should have stuck with an 'easy option'.

First interview transcription is taking a very long time, though it's full of rich information I'm worried it's not focused enough?

January 2012

Made the decision to approach professionals as well as couples. Very grateful to have a particularly supportive elective supervisor who's willing to be flexible according to what I need to do.

February 2012

Now feeling positive about using professionals as well as couples – the ones I've interviewed have had such interesting points to make which might fit well with the couples' views. However, I'm feeling really behind in time – introduction chapter is a bit of a struggle and I still have 3 or 4 professionals interviews to do in March. Neil has been brilliantly patient and flexible about chapter deadlines though, which is a big relief.

It's hard to believe though that the recruitment phase is over now – that in itself feels like a big achievement. Although I'm really grateful for the hard work of the memory team and of Tina in recruiting people, it feels like perhaps I should have agreed a way to be more in control of the recruitment process.

March 2012

It was a huge relief to get Chapter One done, but it felt there was so much that could go into it, that I'd had to miss out a wealth of information.

Though now all the interviews are done and transcripts typed and ready for analysis, that also feels like a huge relief. The study feels much more like it's taking shape.

There is a huge amount of data, 12 transcripts and some up to 50 or 60 pages long, with an enormous list of codes and themes, it is very overwhelming. Though I'm reassured by previous trainees that this is a normal feeling and it does take shape eventually. The looming deadlines are helping me to focus but also starting to engender a bit of panic about the timescales.

April 2012

The couples results are done (bar comments from supervisors) and I'm quite pleased with them. Although it does feel like there is an awful lot more data there, and dozens of different focuses that could be taken.

Now on to the professionals' results – which seems harder for some reason, even though there's far less quantity of transcripts. Perhaps because the 'themes' seem much broader and more diverse?

Appendix 4

**Letter of Approval from Cardiff & Vale University Health Board
Research and Development Committee**



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

19 October 2011

Miss Helen Mitchell
Trainee Clinical Psychologist
Cardiff and Vale UHB
1st Floor
Archway House
77 Ty Glas Road
Llanishen
Cardiff
CF14 5DX

Dear Miss Mitchell

Project ID : 11/MEH/5158 : Coping With Young Onset Dementia: An Exploration Of Adjustment And Support Needs

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Revised documentation as required by the REC in order to obtain favourable opinion
- Evidence of appropriate informed consent training for the CI / PI / delegated researchers

The following amended documentation is approved for use with this study:

Document	Version	Date
Participant Information Sheet: Professionals	2.1	13 September 2011
Participant Information Sheet: Patients and Partners	2.1	30 September 2011
Letter to Professionals	2.1	13 September 2011
Letter to Patients and Partners	2.1	30 September 2011

GP Letter	1.1	30 September 2011
Patient Consent Form	2.1	30 September 2011
Partners Consent Form	2.1	13 September 2011
Professionals Consent Form	2.1	30 September 2011

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the *Data Protection Act 1998*
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the *Human Tissue Act, 2004* (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,



Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC R&D Lead Prof Nick Craddock
 CC Prof Neil Frude, Academic supervisor

Appendix 5

Letter of Approval from the Research Ethics Committee

Miss Helen Mitchell
Trainee Clinical Psychologist
Cardiff & Vale NHS Trust
South Wales Doctoral Programme in Clinical Psychology
1st Floor, Archway House, 77 Ty Glas Road,
Llanishen, Cardiff
CF14 5DX

5 October 2011

Dear Miss Mitchell

Study title: **Coping with young onset dementia: An exploration of adjustment and support needs.**

REC reference: **11/WA/0226**

Thank you for your letter of 30 September 2011, 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.

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.rdforum.nhs.uk>.

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:

<i>Document</i>	<i>Version</i>	<i>Date</i>	
Covering Letter		30 September 2011	
GP Letter	1.1	30 September 2011	
Interview Schedules for couples	1.5	24 June 2011	
Investigator CV			
Letter of invitation for patients and partners	2.1	30 September 2011	
Academic Supervisor's CV		16 June 2011	
Key Collaborator's CV		22 June 2011	
Interview schedule for professionals	1.5	24 June 2011	
Letter of invitation for professionals	2.1	13 September 2011	
Participant Consent Form: Professionals	2.1	30 September 2011	
Participant Consent Form: Patients	2.1	30 September 2011	
Participant Consent Form: Partners	2.1	13 September 2011	
Participant Information Sheet: Patients and Partners and Reply Slips	2.1	30 September 2011	
Participant Information Sheet: Professionals and Reply Slip	2.1	13 September 2011	
Protocol	1.5	24 June 2011	
REC application	3.1	24 June 2011	
Response to Request for Further Information		30 September 2011	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) 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

11/WA/0226

Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

Mr Owen Hughes

Chair

Enclosures: “After ethical review – guidance for researchers”

Copy to: Professor Neil Frude

Professor Nicholas Craddock, Cardiff & Vale NHS Trust

Appendix 6

Letter to sufferers' and partners' General Practitioners

Date

Dr

GP Address

Dear Dr

I am writing to inform you that one of your patients (named below) has agreed to take part in the following research study and has given consent for me to contact you.

Name of patient:

Date of Birth:

Name of Study: Coping with young onset dementia: An exploration of adjustment and support needs.

Participants in this study will be people under the care of the Memory Clinic who have been given a diagnosis of a dementia under the age of 65, together with their partners. The Memory Clinic have distributed information about the study to their patients who fit the inclusion / exclusion criteria. Your patient contacted the researcher to indicate their interest and to agree to take part.

It is planned that 6 – 8 couples will participate in the study. This will involve a single interview with the patient and their partner together, lasting about an hour, with one researcher. No further involvement will be required.

It is not expected that there will be any disadvantages or risks to participants in this study. However, it is acknowledged that it may bring up some difficult emotions. Participants will be offered additional support if required, and are free to decide to take a break, stop, postpone the interview or withdraw from the study, with no consequences for their care.

If you know of any reasons why this patient should not participate in this study, or have information that you think may be relevant to the patient's participation in the study, please contact the researcher below.

A copy of the participant information sheet is enclosed for your further information. If you would like to discuss the study with me in further detail, then please feel free to contact me.

Yours sincerely

Helen Mitchell

Supervised by:

Professor Neil Frude

Trainee Clinical Psychologist

Clinical Psychologist

And Dr Christina Maciejewski
Consultant Clinical Psychologist

Appendix 7

Participant Consent Form – Patient

Appendix 8

Participant Consent Form – Partner

CONSENT FORM for PARTNERS

Title of Project: Coping with young onset dementia:
An exploration of adjustment and support needs.

Name of Researcher: Helen Mitchell

Please put your initials in the boxes to say you agree with the following:

7. I confirm that I have read and understand the information sheet
Dated (30/09/11, version 2.1) for the above study.
8. I have had the opportunity to see the information, ask questions and
have had these answered to my satisfaction.
9. I understand that my participation is voluntary and that I am free to
withdraw at any time without giving any reason, without my partner's
care being affected now or at any time in the future.
10. I understand that the interviews are confidential unless information is
disclosed suggesting that I or someone else may be at risk of harm.
11. I understand that the interview will be audio recorded and the recording
will be kept securely. After the study is completed, this recording will
be destroyed.
12. I agree to take part in the above study.

Name of Participant (Printed) Signature Date

Name of Researcher (Printed) Signature Date

Contact Details for Researcher on the project: Helen Mitchell, Trainee Clinical Psychologist

Appendix 9

Participant Consent Form – Professionals

CONSENT FORM for PROFESSIONALS

Title of Project: Coping with young onset dementia: An exploration of adjustment and support needs.

Name of Researcher: Helen Mitchell

Please put your initials in the boxes to say you agree with the following:

1. I confirm that I have read and understand the information sheet (Dated 30/09/11, version 2.1) for the above study.

2. I have had the opportunity to see the information, ask questions and have had these answered to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any consequences.

4. I understand that the interviews are confidential unless I disclose information suggesting that someone may be at risk of harm.

5. I understand that my interview will be audio recorded and will be securely held. Following the completion of the study, this recording will be destroyed.

6. I agree to take part in the above study.

Name of Participant (Printed) Signature Date

Name of Researcher (Printed) Signature Date

Contact Details for Researcher on the project:

Helen Mitchell, Trainee Clinical Psychologist, Tel: 02920 206464, Email: Helen.Mitchell3@wales.nhs.uk

Appendix 10

Participant Information Sheet – Couples

PARTICIPANT INFORMATION SHEET FOR PATIENTS AND PARTNERS

Research Project: Coping with young onset dementia: An exploration of adjustment and support needs.

Researcher: Helen Mitchell

I would like to invite you to take part in my research study. Before you decide if you want to take part, I would like you to understand why the research is being done. This sheet explains the study and what your participation would involve.

Introduction

The study will explore the experiences of having a dementia in people who are under 65 years of age. A better understanding of the effects of having a dementia at a younger age could help to improve the support provided. I hope to interview people with a diagnosis of dementia, together with their partners, to find out more about their experiences. I also hope to separately interview staff involved in memory clinics, to find out more about their experiences of working in clinics with younger people.

What is the purpose of the study?

I hope this research will help to improve the support and information given to people with young onset dementia. I also hope that this research will help to improve services available to people under the age of 65.

The study is part of my doctoral qualification in Clinical Psychology with Cardiff University.

Why have I been invited?

You have been invited to take part as you, or your partner, have recently attended the Memory Clinic.

Do I have to take part?

It is up to you to decide whether you would like to join the study. I will describe the study throughout this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

The study will involve you and your partner taking part in an interview that will last about an hour. The interview will be with one person (Helen Mitchell), and will be either at XXX Hospital, or at your home, whichever is most convenient for you. I can arrange to reimburse you for travelling expenses if you go to XXX Hospital. I will record the interview so that afterwards it can be analysed.

The interview will be a discussion about your experience of young onset dementia and what has happened to you since the start of difficulties with memory.

I will also send a letter to the patients' GP, to inform them of your participation in the study.

What are the benefits of taking part?

There are no direct benefits of taking part. Unfortunately I cannot offer you payment for taking part. However, the information we gain about your experiences will increase our understanding and may help to improve the experience of patients in the future.

What are the possible disadvantages or risks of taking part?

I do not expect that there will be any disadvantages or risks to you in taking part. However, this may be a sensitive subject and discussing it may bring up some difficult emotions. If you did become distressed during the interview, I can discuss with you what support would be most helpful, such as meeting with a Clinical Psychologist. You can decide to take a break, stop, postpone the interview or withdraw from the study.

What happens when the research stops?

Following the interview, your involvement in the study will end. When the study is completed, it will be used as part of a doctoral qualification in Clinical Psychology. It is also hoped that the study will be published to give health professionals a greater understanding of this area.

If you would like a summary of the study on completion then please let the researcher know.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to me and I will do my best to answer your questions (contact details can be found at the end of this information sheet). You can also speak to the supervisors of the study, Professor Neil Frude or Dr Christina Maciejewski (contact details at the end of this sheet). If you are still unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. You can find details of how to do this on the NHS website (www.nhs.uk).

Will my information be kept confidential?

The interviews will be recorded and the recordings will be stored securely to make sure that they are kept confidential. The information taken from the interview will be made anonymous, again to keep it confidential, and after this has been done the recordings will be destroyed. Direct quotes from your interview may be used, but again these will be made anonymous and all information which could identify you will be removed.

However, if a disclosure is made during the interview that might suggest any potential harm to yourselves or to other people, the researcher will have to report such issues and therefore confidentiality will have to be broken. If this happens, it will be fully discussed with you.

The initial interviews will be conducted by the researcher (Helen Mitchell). Anonymised information will also be seen by the clinical and academic supervisors involved in the study.

What happens if I don't want to carry on with the study?

You can decide at any time to withdraw from the study. Your interview information will then be destroyed. If you decide to withdraw, it will not affect your standard of care now or at any time in the future.

What will happen to the results of the study?

The information gathered from the interviews will be collated into a report as part of doctoral research with Cardiff University. Direct quotes from the interviews will be used in the report to demonstrate the findings of the research, but it will not be possible to identify individuals who participated.

Who has reviewed the study?

The research is being conducted as part of a doctoral qualification in Clinical Psychology with Cardiff University. It is being funded by the NHS. All research in the NHS has to be approved by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the Dyfed Powys Research Ethics Committee.

If you have any queries or concerns regarding participation, please feel free to speak to the researcher. Contact details can be found below.

Contact Details:

Helen Mitchell, South Wales Doctoral Programme in Clinical Psychology

Dr Christina Maciejewski, Consultant Clinical Psychologist

Professor Neil Frude, South Wales Doctoral Programme in Clinical Psychology

Appendix 11

Participant Information Sheet – Professionals

PARTICIPANT INFORMATION SHEET for PROFESSIONALS

Research Project: *Coping with young onset dementia: An exploration of adjustment and support needs.*

I would like to invite you to take part in my research study. Before you decide if you want to take part, I would like you to understand why the research is being done. This sheet explains the study and what your participation would involve.

Introduction

The reason for the study is to explore the experiences of couples where one person has a dementia at a younger age (under 65). A better understanding of the impact of this at a younger age could help to inform memory clinics in this area. I hope to do this by conducting interviews with health professionals involved in the treatment and care of younger people with dementia, as well as patients and their partners / spouses, to find out more about their experiences.

What is the purpose of the study?

I hope that this research will help to improve the support and information given, and will help services to provide advice on coping with memory difficulties and / or dementia at a younger age. I also hope that this research will lead to recommendations for improving services available for younger people in this area, and to suggestions for further research.

The study will also be used as a required part of a doctoral qualification in Clinical Psychology with Cardiff University.

Why have I been invited?

You have been invited to take part as you have been involved in a professional capacity with treatment and / or support of patients under 65 with a dementia.

Do I have to take part?

It is up to you to decide whether you would like to join the study, which will be described throughout this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason, and without consequence.

What will happen to me if I take part?

The study will involve you taking part in an interview that will last about an hour. The interview will be with one person (Helen Mitchell), and will be either at XXX Hospital, or at another clinical base if this is preferable to you. I will record the interview so that afterwards it can be transcribed and analysed. The interview will focus on your experiences and views of the treatment and/or support of younger people with a dementia, and your views on the impact and the coping mechanisms that people use in this situation. Nothing else will be required.

What are the benefits of taking part?

There are no direct benefits to you of taking part in this study. Unfortunately I cannot offer you payment for taking part. However, the information gained about your experiences and views will increase our understanding in this area, and may help to improve the experience of patients in the future.

What are the possible disadvantages or risks of taking part?

It is not anticipated that there will be any disadvantages or risks to taking part. However, if for any reason you have difficulties during the interview, the researcher can discuss what support would be most helpful to you.

What happens when the research stops?

Following the interview, your participation in the study will end. When the study is completed, it will be used as part of a doctoral qualification in Clinical Psychology. It is also hoped that the study will be published to allow others who work in similar services to gain a greater understanding of this area.

If you would like a summary of the study on completion then please let the researcher know.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to the researcher, and I will do my best to answer your questions (contact details can be found at the end of this information sheet). You can also speak to the supervisors of the study, Professor Neil Frude or Dr Christina Maciejewski (contact details at the end of this sheet). If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from the NHS website (www.nhs.uk).

Will my information be kept confidential?

The interviews will be recorded and the recordings will be stored securely to ensure confidentiality. The information taken from the interview, including direct quotes, will be made anonymous, again to maintain confidentiality, and all identifiable information will be removed. Following data analysis, the recordings will be destroyed.

However, if a disclosure is made during the interview that indicates or suggests any potential harm to yourself or other people, the researcher will have to report such issues and therefore confidentiality will have to be broken. Any such developments will be fully discussed with you.

The initial interviews will be conducted by the researcher (Helen Mitchell). Anonymised information will also be seen by the clinical and academic supervisors involved in the study.

What happens if I don't want to carry on with the study?

You can decide at any time to withdraw from the study. If you decide to withdraw, your interview information will be destroyed, with no consequence to you of withdrawal from the study.

What will happen to the results of the study?

The information gathered from the interviews will be collated into a report as part of doctoral research with Cardiff University. Direct quotes from the interviews will be used in the report to highlight elements of the research, but it will not be possible to identify individuals who participated.

Who has reviewed the study?

The research is being conducted as part of a doctoral qualification in Clinical Psychology with Cardiff University. It is being funded by the NHS. All research conducted within the NHS has to be approved by the local Research and Development and Research Ethics Committees. This study has been reviewed by the Dyfed Powys Research Ethics Committee.

If you have any queries or concerns regarding participation, please contact the researcher. Contact details can be found below.

Contact Details:

Helen Mitchell, South Wales Doctoral Programme in Clinical Psychology

Dr Christina Maciejewski, Consultant Clinical Psychologist

Professor Neil Frude, South Wales Doctoral Programme in Clinical Psychology

Appendix 12

Semi Structured Interview Schedule – Couples

LARGE SCALE RESEARCH PROJECT

Study Title: Coping with young onset dementia: An exploration of adjustment and support needs.

Qualitative Semi-Structured Interview Schedule - Couples Interview

The main stem questions are in bold, and the text in italics is intended as prompts to be used if necessary.

Stem Question: Background Information

- How old are you both?
- How long have you been together?

Stem Question: History of dementia

When did you first notice that there were difficulties with memory? (for both)

Prompts:

- *What did you notice?*

At what point did you decide you needed to see someone about it?

Prompts:

- *Can you tell me about the appointments you had (with the Memory Team) ?*

Stem Question: Relationships

Have your memory difficulties / dementia had any effect on your relationships?

Prompts:

- *Has there been any change in your relationship with each other, or with other people in your life?*

Stem Question: Impact

How else has the dementia affected your life?

Stem Question: Coping

Can you tell me about how you both coped with the memory difficulties?

Was this experience different to things you have had to cope with in the past?

What do you think was most or least helpful?

What advice would you give to others who are going through the same thing as you?

Stem Question: Support

What kind of help did you have?

What was most helpful?

What was least helpful?

Were you offered formal support (*e.g. a support group*)?

Was there anything that you would have wanted to be offered or to be available that would have helped you more?

Stem Question: Advice and Anything else

How would you advise professionals to support people who are going through the same thing as you?

Is there anything else you would like to say about your experiences?

Appendix 13

Semi Structured Interview Schedule – Professionals

LARGE SCALE RESEARCH PROJECT

Study Title: Coping with young onset dementia: An exploration of adjustment and support needs.

Professionals Interview - Qualitative Semi-Structured Interview Schedule

Stem Question: Background information

What is your role?

What is your experience of working with younger people with dementia?

Stem Question: Working with younger people

What are the similarities or differences in working with those who are younger to working with those who are older?

Stem Question: Coping & support needs

Can you bring to mind any recent cases you have worked with – what was the impact on them or their families?

Is there anything you have noticed couples use as ways of coping? What have you noticed as being more or less helpful for them?

What kind of support do you think would be most useful for a younger person in this situation?

Stem Question: Professional impact

How do you feel about working with someone who is younger at this time?

Did you have additional training, support or supervision for these kinds of issues in your work? What are your thoughts about this? What would you find helpful?

Stem Question: Advice and anything else

What would you advise to another professional working with a younger person with a dementia?

How would you advise a younger person you were working with about how to cope with the dementia and associated life changes?

Is there anything you would like to add?

Appendix 14

Introductory letter – Couples

Dear Sir/Madam,

This letter has been sent to you on my behalf by a professional working at the Memory Clinic. This letter has been sent to a number of people who have attended the Memory Clinic because they have been given a diagnosis of dementia under the age of 65.

I am writing to introduce myself, and to send you information about a research study I am carrying out. I hope that you may be interested in participating.

I am a Trainee Clinical Psychologist with a keen interest in dementia, especially in people under 65 years of age. This comes from working for a number of years with people with dementia, and also from having worked at the Memory Clinic previously. The study, which is part of my doctoral training, will look at how younger people cope with this issue, and how it has affected their lives. I am hoping to talk to people along with their partners. I hope that this research will add to knowledge, and help to improve the services available for younger people with dementia.

I have enclosed some further information about my research and I would be very grateful if you would take the time to read it. If you and your partner would both like to participate in the study, please complete the two attached reply sheets together and return them to me in the enclosed stamped addressed envelope. If you would like to discuss the study with me in further detail, then please feel free to contact me.

Many thanks

Helen Mitchell

Trainee Clinical Psychologist

Supervised by Professor Neil Frude

Clinical Psychologist

And Dr Christina Maciejewski
Consultant Clinical Psychologist

Appendix 15

Introductory letter – Professionals

Dear Sir/Madam,

This letter has been sent to you on my behalf by a professional working at the Memory Clinic. This letter has been sent to a number of professionals in Cardiff who work in the field of dementia.

I am writing to introduce myself, and to send you information about a research study I am carrying out. I hope that you may be interested in participating.

I am a Trainee Clinical Psychologist with a keen interest in dementia, particularly young onset. This comes from working for a number of years with people with dementia, and also from having worked at the Memory Clinic previously. The study, which forms part of my doctoral training, will explore the impact of a dementia at a younger age and psychological processes that affect coping and adjustment. I hope that this research will add to the clinical evidence base, and help to inform the development and delivery of services for younger people with dementia.

I have enclosed some information about my research and I would be very grateful if you would take the time to read it. If you would like to participate in the study, please complete the attached reply sheet and return it to me in the enclosed stamped addressed envelope. If you would like to discuss the study with me in further detail, then please feel free to contact me.

Many thanks

Helen Mitchell
Trainee Clinical Psychologist

Supervised by Professor Neil Frude
Clinical Psychologist

And Dr Christina Maciejewski
Consultant Clinical Psychologist

Appendix 16

Reply sheets – Couples

REPLY SHEET for PATIENTS

Research Study: Coping with young onset dementia: An exploration of adjustment and support needs.

Researcher: Helen Mitchell

Dear Helen

I have read the information about your research study and am interested in participating with my partner. Please contact me to discuss it further.

Name: _____

Address: _____

Telephone number(s): _____

Please say when you would prefer to be contacted:

Preferred Days _____

Preferred Times _____

Any other comments: _____

Signed (Patient): _____ Today's Date: _____

REPLY SHEET for PARTNERS

Research Study: Coping with young onset dementia: An exploration of adjustment and support needs.

Researcher: Helen Mitchell

Dear Helen

I have read the information about your research study and am interested in participating with my partner. Please contact me to discuss it further.

Name: _____

Address: _____

Telephone number(s): _____

Please say when you would prefer to be contacted:

Preferred Days _____

Preferred Times _____

Any other comments: _____

Signed (Partner): _____ Today's Date: _____

Appendix 17

Reply sheet – Professionals

REPLY SHEET for PROFESSIONALS

Research Study: Coping with young onset dementia: An exploration of adjustment and support needs.

Researcher: Helen Mitchell

Dear Helen

I have read the information about your research study and am interested in participating. Please contact me to discuss it further.

Name: _____

Address: _____

Telephone number(s): _____

Email: _____

I would prefer to be contacted by **telephone / post / email** (delete as appropriate)

Please say when you would prefer to be contacted:

Preferred Days / Times: _____

Any other comments: _____

Signed: _____ Today's Date: _____

Appendix 18

**Excerpts from transcripts of a couples and a
professionals interview demonstrating the data
analysis procedure**

Transcript 1

Holding on to hope

P: No we did, in fact I told all of his family, we treated it as such good news that we kind of its not dementia, its whatever's happened's happened, they have nothing to tell us why, but all we know its going to be a long time before things get worse.

Explanation
Uncertainty
Treatment

R: up till then you'd been talking about it being dementia and its going to get worse. Between the two of you had you been able to have conversations about that?

Reluctance
Avoidance

P: No. Its not something that he likes to talk about is it, about the future and how things get worse. It's not something

Avoidance

Experience
Worry
Fear

S: I think I'm frightened im going to end up a vegetable you know like my mother, she couldn't talk or anything could she, she just sat there like that.

- Emotional
- Expectations/
Model of
AD

R: so that's not something youre wanting to think about quite understandably. So you got to the 2 of you where you were quite positive

Sadness
Loss
Fear

S: I used to go and see my mother in and I'd break my heart she'd be sat in a chair in the corner on her own.

Comparing
with
others

P: I know now that some of the people we mix with a few are unable to talk and that's one of his fears, he will sometimes say you know why I talk all the time, he will just talk because he needs to talk

Model of
AD
- Emotional
reactions

Struggle
for control

S: I don't give anybody else a chance to speak do I

Worry/fear
Overwhelm

P: That's right and he'll say that's because my fear is I wont be able to. It's a huge fear for you isn't it.

Fear for
future

S: Yes. Okay.

R: So there was all that process on and eventually something was decided?

Feeling
let down

P: No its never been decided.

S: they keep saying I'm a special boy.

Uncertainty
Treatment

Comparatory
rel's

P: Absolutely, life would be very lonely if it wasn't for the Alheimers society, literally. Theyre the people who've put us in contact with friends now who I would say have taken the place of family, I feel so strongly.

Social
Identity

S: we went on holidays to Canada.

P: we did yeah, I hadn't been well and and, two couples, have rang me regularly just to see how I am

Feelings
accepted

S: And how I am

Positive
rel's

P: Yeah always, and its just, I'd go as far to say it's a joy, it makes all the difference to our lives.

*

Comparing
with others

S: She's got her hands full

P: Yeah, everybody has different needs don't they but it just makes a difference cause you know what people are going through, you know whether she would say yeah I've cried all day today and I can think yeah I understand that, or I've had a great day today.

Shared
Identity

- Responsibility
Shared
Experience

S: She likes going to the singing with us.

New
activities

Comparatory
rel's
Isolation
(X)

P: We all like going to the singing don't we. So whatever I would take part in as much as I can, I would take part in, and because that's our future, I see it as the future for us because without those people and the activities that we go along to, we would just be very very lonely, extremely. People are very busy they get on with their lives, but they don't really understand dementia and they don't really want to, its seen as mental illness

Practical
strategies

- View of
dementia
- Social
- Systemic
- Model of AD

Other lack
awareness

S: Its as if it's a disease you can catch. That's how I look at it, that's how I think people, I don't see any of my family so much now do I.

View of
self
Worry
Past identity

P: No not at all, so we are very much, I feel it must be very hard for our son and daughter, because you know our life, whereas we were always when they were growing up we were he was always very extrovert it's always been open house, we always had garden full of children and I've always liked to entertain so we'd have a house full of people for Christmas, the new year, I was always cooking, and can't believe I did it cause Ive always worked but hey I did it,

- Systemic
- Emotions
- Core
identity

Transcript P4

P: In general it's fairly its taught that people with younger onset dementia will deteriorate more drastically I suppose and rapidly than older people and will probably not achieve a normal lifespan, so if you develop dementia when you are in your late 70's or early 80's, you might live until you are 90 and that is maybe as long as you would have lived anyway, whereas if you develop it when you are say early 50's then the chances are that you will become to the end of your life by the time you are 60 say, so there is quite a big change and there is I think a more drastic change as well, in that older people with dementia often become pleasantly confused if you like and don't have an enormously difficult behaviours, we see the ones that are very difficult but a lot of people we never see are slowly getting more forgetful and just carrying on in their own sweet way with help and don't cause any great difficulties but younger people I think in general, they more often have some behaviours or some aspects to their condition which are more problematic and more likely perhaps to lose speech and understanding at quite an early stage, so there is more to it I think, there is a slightly more changes probably in general

Differences
in challenges
symptoms

Left part
of dementia
interestless

Complexity/
challenge

Communication
impact

R: The road to diagnosis is difficult for younger people I suppose because of things like that, so is that a slower process? Or is that the same ?

P: I think people are a little thorough about trying to diagnose a young person, I think want to try and hope it isn't (laughing) and so they try to find all other sorts of other reasons that it might cause these same symptoms and look at depression for example, some other neurological things or whatever and so perhaps compared to someone already 85 they might not go down the road of doing absolutely every single test because especially if someone has a very typical onset and are very low key thing then they'll probably say it's more than likely dementia and this is what we are going to do about, as opposed to someone young who presents maybe, early 50's or late 40's even, they think we must try and get this person better or else we're condemning them to an awful life so I think there is a lot more thoroughness probably.

Uncertain
Reluctance
'to be it'dh'
Necessary?

Prod.
challenges

Series

Testing/
diagnosis

Medical
uncertainty

Identification?
Responsibility

R: In terms of medication, is that the first line if people are suitable for it?

P: I would suggest probably when someone has a definite or at least as definite a diagnosis as you can make, because nobody actually says well you definitely got Alzheimer's they say you probably got Alzheimer's don't they? And I think you would

Uncertainty

be offered medication quite early in order to try and prolong the good times rather than go downhill more rapidly.

High expectations

R: What do you think of peoples' expectations of things like medication in younger people particularly?

Conley for older people

P: Well I think a lot of them haven't even thought about it because they never thought of it happening to them or maybe it hasn't happened to their parents or anything and I think people these days often are in the oh there is a tablet for it so you will be ok, and we have to be very careful to explain to people look, this isn't going to work for everybody, going to give you a trial of it and if it works brilliant, and if it doesn't, then we may suggest something else, but maybe you are not the one person that it's not going to work for you know and we are going to have to think of other ways to help you, so I think you have to be very honest about it when you start prescribing that it's not going to be a cure, certainly not a cure for anybody, even if it works it's only going to be helping things to be less difficult, but I mean I have seen some wonderful improvements with medication and you know it is not going to last forever but it makes their life more worthwhile for the time being.

Societal view

Upstence

Prof. challenges

Upstence

Uncertainty

R: If you were to think of a piece of advice when you are meeting a younger couple or person in the earlier stages of their process when they get their diagnosis, would there be something that you would particularly want them to know or advise them?

Comparing?

P: I suppose perhaps the most thing that I hope they will take on is that there is a service they can access, that they are not, it's not so rare that there won't be lots of other people with the same problems that they can hear about and get to know and so on and that there are people with expertise who can help them because I think some people younger people think it is so rare and don't know anybody else that this has ever happened to and probably they haven't, they don't know personally anybody else this has happened to until they are introduced to a group of people who have it and then I think that for most people that can be quite helpful in making some sense of it really, so I often say well look this is quite rare in your age group that this has happened to but certainly there are still lots of people around with the same problem, and if you wanted to you could meet them and join in and see that you are not the only one but I think that would be one of the things you would always be saying really.

Peer support

The coping

Normalising

Normalising/ comparing/ or isolating?

Shared identity

Peer support

Appendix 19

**Table showing the Superordinate, Master themes and
breakdown of Master themes for all participants**

Appendix 19

Superordinate, Master themes and breakdown of Master themes - COUPLES

Superordinate Themes	Master Themes	Breakdown of Master Themes
View of dementia	Early symptoms “There’s something wrong” Finding alternative explanations Model of dementia	
Living with a diagnosis	Diversity of emotions	Fear of the future Feeling of being stigmatised
	Unpredictable lifestyle	Dealing with uncertainty Holding on to hope Loss of activities
Effect on couple relationship	Change in roles Couple identity Control and responsibility	
Relationships with others	Lack of awareness Isolation	
Coping strategies	Social identity	Developing compensatory relationships Finding a group identity
	Practical strategies	Keeping busy Distraction
	Emotional strategies	Building confidence / self esteem Acceptance Positive thinking Avoidance
Reflections on treatment and services	Uncertainty Need for increased awareness Timeliness of post diagnosis support	

**Superordinate, Master themes and breakdown of Master themes –
PROFESSIONALS**

Superordinate Themes	Master Themes	Breakdown of Master Themes
Coping strategies of sufferers and carers	Utilising uncertainty	Holding on to hope Predicting the future
	Emotional strategies	Searching for meaning Comparing with others Maintaining identity Holding on to control
	Practical strategies	Keeping going Talking to others
Factors affecting coping by sufferers and carers	Individual factors	Emotional reactions Impact of the dementia Hopes and expectations
	Relational factors	Impact of role changes Effect on couple relationship
	Systemic factors	Impact on multiple generations Isolation Societal values
Contextual factors in working with younger people with dementia	Challenges for professionals	Identification with service users Dealing with uncertainty Professional impotence Coping strategies
	Service challenges	Diagnosis issues Service dilemmas Societal view of dementia
	Supporting coping processes	Informational support Supporting independence