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Thesis: Pritchard (2016) "An exploration of the perceptions of younger people with dementia about hope", University of Southampton, Faculty of Health Sciences, DClInP Thesis, 1-219.

Data: Pritchard (2016) An exploration of the perceptions of younger people with dementia about hope. URI [dataset]



**UNIVERSITY OF SOUTHAMPTON**

FACULTY OF HEALTH SCIENCES

Volume 1 of 1

**An exploration of the perceptions of younger people with dementia about hope**

by

**Jane Pritchard**

Thesis for the degree of doctorate in clinical practice (DClinP)

June 2017



UNIVERSITY OF SOUTHAMPTON

## **ABSTRACT**

FACULTY OF HEALTH SCIENCES

Thesis for the degree of doctorate in clinical practice

### **AN EXPLORATION OF THE PERCEPTIONS OF YOUNGER PEOPLE WITH DEMENTIA ABOUT HOPE**

Many people with dementia report that hope is important to them. Despite this, people with dementia experience low levels of hope and high levels of hopelessness. This experience is different from that of people with terminal illness who typically report high levels of hope. Facilitating hope in people with dementia has been described as an integral part of caring and vital to the work of nurses as well as central to person-centred care. Nevertheless, studies to date lack detail about how staff might recognise, explore and promote hope.

The aim of the research was to examine the phenomenon of hope from the perspective of younger people (those under 65) with dementia, in order to generate new understanding, and enable community based healthcare professionals to support well-being. The study used a modified diary-interview method. Participants were given a camera and asked to take pictures of whatever made them feel hopeful. During a post-diary semi-structured interview, a conversation about hope took place. Findings have indicated that hope is important to younger people with dementia. People hoped for a future, and five themes in particular were elicited about what people hoped for; good health for themselves and others; for enjoyable events to take place; for continued contact with other people; for success in their endeavours; and for a better world.

Sources of hope were: the surrounding environment; 'taking action'; the person's own internal resources, and keeping connected to others. An over-arching theme was 'defying dementia' where participants demonstrated resistance to negative stereotypes. Living with dementia did not curtail hope, although it could be weakened when participants felt 'cast adrift'. Further research is required to ascertain whether hope should be a more central part of conversations professionals undertake with people with dementia.



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## DECLARATION OF AUTHORSHIP

I JANE PRITCHARD, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

An exploration of the perceptions of younger people with dementia about hope

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before

Signed: .....

Date: .....



## Acknowledgements

I would like to thank the people with dementia who took part in this study, for generously giving their time, and for allowing me to hear their stories.

I also owe a great debt to my project supervisors Dr Ruth Bartlett and Dr Carol Rivas for their help and support, and to my past project supervisors who have helped me during this journey; Professor Judith Lathlean, Dr Laetitia Zeeman and Dr Lucy Simmons.



## Definitions and Abbreviations

AD	Alzheimer's Disease
DeNDRoN	Dementias and Neurodegenerative Diseases Research Network
NHFT	Northamptonshire Healthcare NHS Foundation Trust
NHS	National Health Service
Pwd	People with dementia



# Chapter 1: Introduction

## 1.1 Background

Dementia has been defined as a syndrome where there is deterioration in memory, thinking and behaviour and the ability to perform everyday activities (WHO, 2017). There are many different forms of dementia, Alzheimer's being the most common (Alzheimer's Society, 2015). According to a recent report there are estimated to be over 850,000 people with dementia in the UK, 42,325 of whom have early-onset dementia (onset before the age of 65) (Alzheimer's Society, 2014).

Dementia (especially Alzheimer's disease) has been described as having three different stages; early or 'mild' stage where minor changes are seen in the person's abilities and behaviour such as mislaying items around the house and losing track of the day or date. A 'moderate' stage where people need more help managing their day-to-day life and may need reminders to eat dress and use the toilet, and late or 'severe' stage where the person becomes totally dependent on others and experiences difficulties such as recognising familiar objects, eating and walking (Alzheimer's Society, 2015). However, the stage model is not universally accepted (Sixsmith et al, 1993) having been described as deterministic, and failing to take account of how social factors such as loss of personhood and poor quality care affects disease progression (Kitwood, 1998). Also, it is recognised that there is individual variation in symptoms and different forms of dementia (Alzheimer's Society, 2015). This has prompted an interest in the subjective world of people with dementia, and in understanding what affects their experience.

One growing area of interest is on the experience of hope. Research has shown that many people with dementia report that hope is important to them (Clare, 2002; Aminzadeh et al, 2007; Phinney, 2008) while others experience low levels of hope (Chapman, 2011) and high levels of hopelessness (Nygård & Borell, 1998; Svanström & Dahlberg's, 2004). This experience is different from that of people with terminal illness whose hope remains (Buckley & Herth, 2004; Sanatani et al, 2008; Cutcliffe & Zinck, 2011) and who typically report high levels of hope (Duggleby & Wright, 2005). Facilitating hope in people with dementia has been described as an integral part of caring and vital to the work of nurses (Cutcliffe, 1996; Cutcliffe & Grant, 2001; Cotter, 2009) as well as central to person-centred care (Martin, 2009; Hill et al, 2010). Nevertheless, studies to date lack detail about how staff might recognise, explore and promote hope in their practice beyond breaking diagnosis sensitively (Aminzadeh et al, 2007) and within the context of a caring relationship (Cutcliffe & Grant, 2001). Similarly, the possibilities that hope could offer people with dementia within a mental health 'recovery' approach (Woods, 2007; Adams, 2010) or a citizenship approach (Bartlett & O'Connor, 2007) show potential, but to date lack empirical study.

The concept of hope is particularly salient in the context of younger people with dementia (those under 65 years of age) who it has been argued may have different needs to older people (Keady & Nolan, 1999; Beattie et al, 2002). They are more likely for example to be physically fit and active, and to be aware of their problems, increasingly the likelihood of frustration and distress (Jefferies & Agrawal (2009). Younger people are commonly still in paid work when symptoms begin, and may need to retire early bringing financial hardship (Woods, 1999) especially where there are pre-existing financial commitments such as mortgages and loans (Jefferies & Agrawal, 2009). Their younger age makes them more likely to have dependent children, who are likely to be impacted by their illness (Keady & Nolan, 1997; Cox & Keady, 1999; Walton, 1999) especially if the dementia may be genetic (Gilliard, 1999). Younger people typically experience a delay in diagnosis and treatment (Harris & Keady, 2004) due to a multitude of factors including unusual symptoms, rarer forms of dementia being common, misdiagnosis, and lack of experience of younger people on the part of health care providers (Hunt, 2011). There is also concern that younger people and their families may be marginalized, socially isolated and lack support (Kaiser & Panegyres, 2006) encountering a lack of age appropriate services (Beattie et al, 2002).

To date studies that have mentioned the importance of hope have been almost exclusively qualitative. For example, the need to retain hope was a spontaneously elicited and central theme of focus groups conducted by Harris (2002) and also focus groups and interviews carried out by Pipon-Young et al (2012) who asked people diagnosed with dementia before the age of 65 about their experiences of living with the illness. Pipon-Young et al (2012) noted the similarities with the 'Recovery' approach to mental healthcare, and concluded that dementia services should begin to focus on how they can engender hope. A review of three autobiographies written by younger people with dementia by Basting (2003) found that all authors expressed hope that their writing would help others, while Graboyes (2012) who was 49 when he was diagnosed with dementia has described the importance of hope to him which he said gave him optimism and the ability to see that life was worth living. Not all studies have demonstrated that hope was present in younger people with dementia however; Nygård & Borell (1998) for example found that living with dementia had a negative impact on people's hope.

There are only a handful of studies which have explicitly sought to understand hope in people with dementia. A concept analysis has been conducted by Cotter (2009), while Cutcliffe & Grant (2001) examined how nurses inspire hope in people with dementia, Chapman (2011) sought to quantitatively measure hope in older people with dementia and to understand if it was related to stigma. Only Radbourne (2008; see also Wolverson et al 2010) asked people with dementia about

their hope however. In her study of ten older people with early-stage dementia, she conducted semi-structured interviews to explore their hopes, and what helped and hindered them. Hope was found to be present, and vital to participants. This hope was threatened by living with old age and dementia, and they worked to achieve a *“position of contentment or resolution”* (Radbourne, 2008; p59). Participants were found to use coping behaviours, and worked to keep healthy and maintain relationships, in order to *“keep living, and keep living well”* (Radbourne, 2008, p71). There is therefore a need for further exploration of the concept of hope and whether it is useful to people with dementia, particularly younger people whose opinions do not yet appear to have been sought. Qualitative methodologies should date been able to provide some useful insights regarding hope, although further, more in-depth study is needed.

The current study therefore used qualitative methods to explore perceptions of hope from the perspective of people with dementia. In the study, as with Radbourne (2008), people with dementia were asked directly about hope, rather than asking nurses, as in Cutcliffe & Grant (2001) and it sought to understand the views of younger people with dementia about hope, rather than older people as in Radbourne (2008). For the purposes of this study younger people are defined as people under 65 years, the standard cut off age for adult and older adult mental health services in the UK. The study also used photo diaries not seen in either of these studies in an attempt to elicit rich data. Photographs served as memory prompts for participants, facilitating discussion and allowing a richer insight into their world. The study sought to understand whether participants believed that hope was helpful, where it came from, and what helped and what hindered their hope; be it the actions of individuals, society or their own ideas and coping strategies. It was hoped that with this knowledge it would be possible to inform and improve the care delivered by staff working with people with dementia in community settings.





## **Chapter 2: Literature Review**

### **2.1 Overview**

An initial review of the literature using CINAHL, EBSCO Host and OVID databases and search terms 'hope AND dementia' returned only one study which offered perspectives on the hope experience of people with dementia (Wolverson et al, 2010).

The search was then widened using search terms 'hope AND cancer,' 'hope AND palliative', 'hope AND recovery', 'hope AND nursing', 'hope AND spirituality' and hope AND disability' which helped to locate studies about hope in other populations. These were hand searched for other studies of interest and for reference to dementia and other types of cognitive impairment. These studies were then retrieved and the process repeated.

Search terms 'dementia AND experience', 'dementia AND perspective' and 'dementia AND positive' yielded a large number of studies which gave the experiences and perspectives of people with dementia. Papers were hand searched for mention of hope or related concepts. Several further studies were identified which were obtained and these were then hand searched.

Themes generated from this search and an overview of the literature are discussed in section 2.1, together with details of two subsequent searches; in July 2015 and September 2016. Section 2.2 defines hope, and sections 2.3 to 2.10 explore different perspectives on hope in more detail.

### **2.2 Themes generated from the literature search**

All relevant papers were themed by the underlying theoretical assumptions of the authors, generating seven categories which can be seen in figure 1 on the following page. These seven categories will be discussed in more depth in the following sections of this literature review.

1. Biomedicine
2. Mental Health Recovery
3. Critical approaches including disability and social models
4. Lived Experience
5. Nursing Perspectives
6. Psychological Perspectives
7. Spirituality

Figure 1 The seven categories generated from literature search

In July 2015, the original search was repeated due to the fact that 29 months had passed since the original search was undertaken. This was again updated in September 2016 as a significant amount of time had again passed. On both occasions DelphiS was used and in addition to 'hope AND dementia', search terms 'hope AND Alzheimer's Disease' and 'dementia AND positive' were added, returning 780 papers in July 2015 and a further 46 in September 2016, a total of 826 papers. Other types of dementia such as vascular dementia and lewy-body dementia were not used as search terms as it was anticipated that these would be picked up through the existing terms.

After removal of duplicates, letters, book reviews, conference proceedings, poster presentations, news stories, articles with no identifiable author and those which were not in the English language a combined total of 152 articles remained. A total of 39 articles were then removed as these concerned the hope of carers of people with dementia rather than people with dementia themselves. Another paper concerned people with brain injury rather than dementia and so this was removed.

A significant number of papers (n=102), mostly from the search 'Dementia AND Positive' were then excluded as they did not concern hope or hope related concepts. Most articles which fell into this category (n=62) were biomedical studies using phrases such as 'Ubiquitin-positive', 'Tau-positive', or 'screened positive for dementia' in the title. Others excluded were ten papers about dementia in people who were HIV-positive (not about hope), studies about 'positive effects' of various interventions, and where these did not describe impact on mood or hope they were excluded from further analysis. Table 1 on the following page summarises these findings.

Action	Hope AND dementia	Hope AND Alzheimer's	Dementia AND positive	Total
<b>Total number papers returned</b>	<b>102</b>	<b>178</b>	<b>546</b>	<b>826</b>
Excluded as duplicates	55	67	374	496
Excluded as not in English	4	4	2	10
Excluded as either; letter, book review, description of conference, poster presentation, news story or no author	16	42	18	76
Excluded as about carers only	3	4	32	39
Excluded as not about people with dementia	0	1	0	1
Not about hope or related concepts	2	0	100	102
Total excluded:	80	118	526	724
<b>Total remaining</b>	<b>22</b>	<b>60</b>	<b>20</b>	<b>102</b>

Table 1 Results of DelphiS searches on July 2015 and September 2016 (combined results)

The remaining 102 articles were then subjected to more detailed thematic analysis, the results of which can be seen in table 2 on the following page.

Theme			Hope and Alzheimer's Disease	Hope and Dementia		Hope & Positive
Biomedical	Understanding biology of dementia	Hope through better understanding of causes of dementia	10	1		0
	Detection of dementia	Hope for quicker diagnosis	2	0		0
		Early diagnosis as hope	2	0		0
	Preventing dementia	Hope for prevention through controlling risk factors	1	0		0
		Hope for prevention via pharmacology / scientific treatment	12	2		0
	Medical treatments for dementia	Hope for drug treatment for dementia	27	5		0
		Positive outcome of drug treatment	0	0		2
Political & Strategic	Attention given to dementia	Health policy/attention to dementia	1	1		0
	Understanding what 'dementia positive' means	What 'dementia positive' means in policy	0	0		1
Psychosocial	Understanding hope and related concepts	Understanding the hope experience	0	3		1
		Measuring mood related neuropsychiatric symptoms seen in dementia	0	0		4
		Debating whether hope is lost through failed drug treatments	3	6		0
	Person-centred care	Hope through person-centred care	1	0		0
		Positive outcomes through person-centred care	0	0		1
		Positive changes and strengths seen in dementia	0	0		3
	Psycho-social intervention	Hope through psycho-social intervention	1	4		0
		Increase in positive affect through psycho-social intervention	0	0		4
		Positive outcomes through psycho-social intervention	0	0		4
TOTAL			60	22		20

Table 2 Results of DelphiS literature search; how hope is represented in the literature

The analysis revealed that a biomedical understanding of hope dominated the literature with 64 papers. Psychosocial related papers made up another sizable number, with political and strategic articles making up a small number (n=3) which can be seen in figure 2 below.

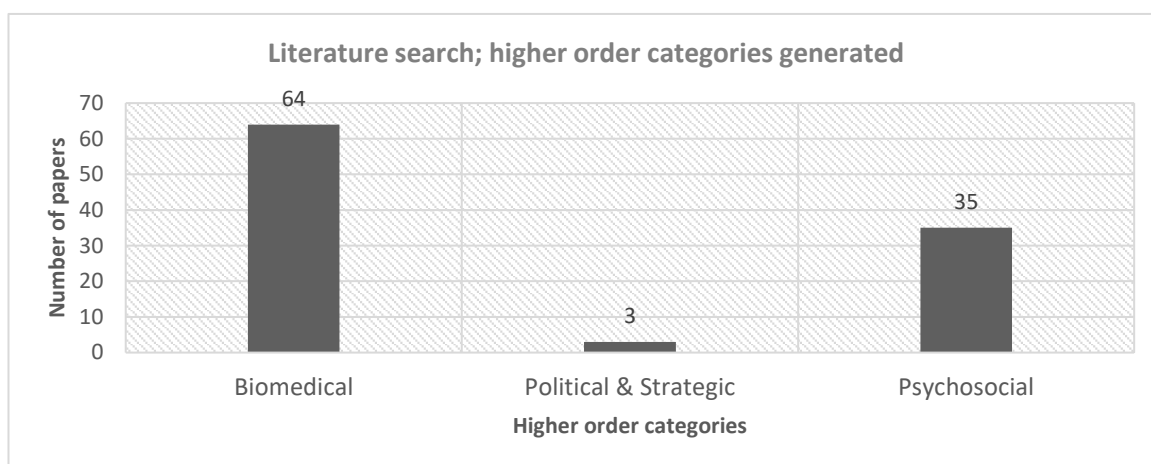


Figure 2 DelphiS literature search; higher order categories generated

Biomedical hope involved a particular focus on medical treatments for dementia which were seen to be creating hope through the possibility of cure or effective treatment. Thirty-four papers of this type were returned. There was also hope expressed for preventing dementia (through for example the creation of a vaccine) and fifteen papers fell into this category. Papers which concerned the furthering of knowledge about dementia (in order to better target future treatments) were seen in eleven articles, and in four articles quicker detection and diagnosis was described as key to hope (see figure 3 below).

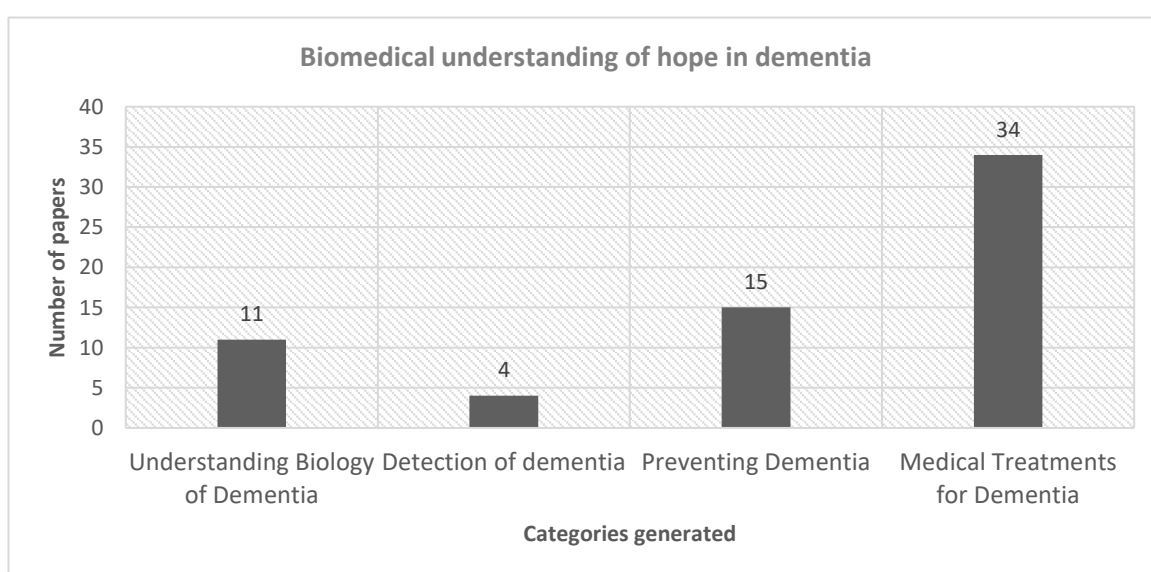


Figure 3 DelphiS literature search; Biomedical understanding of hope

## Chapter 2

In none of the biomedical articles was hope itself investigated or measured (this was done in some of the other approaches) and people with dementia were not consulted. It was assumed in each that an increase in hope would result from the good news story each told. Examples of this were an editorial by Doraiswamy (2003) entitled 'Interventions for mild cognitive impairment and Alzheimer Disease: new strategies, new hope', and Feng et al's (2009) literature review; 'Neural stem cells and Alzheimer's Disease: challenges and hopes'. All biomedical papers reviewed quantitative research only, with no qualitative studies found.

Three articles (O'Connor, 2009; Sokol, 2013; Lin & Lewis, 2015) took more of a political and strategic perspective. The first two argued that attention being given to dementia through national dementia strategies in the UK and USA respectively brought hope to many people (this was not measured). Lin & Lewis meanwhile sought to understand what being 'dementia positive' meant when the phrase was used in policy documents (this was an intentional focus on strengths and person-centred values). This can be seen in figure 4 below.

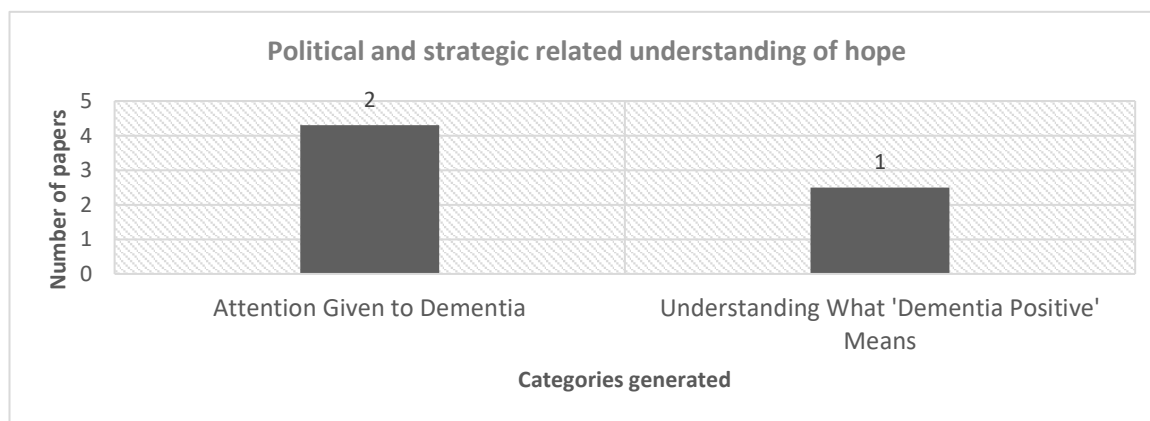


Figure 4 DelphiS literature search; Political and strategic understanding of hope

The third overarching theme was a 'psychosocial' understanding of hope (see figure 5 on following page). This included five studies where hope and related concepts were discussed within the context of person-centred care.

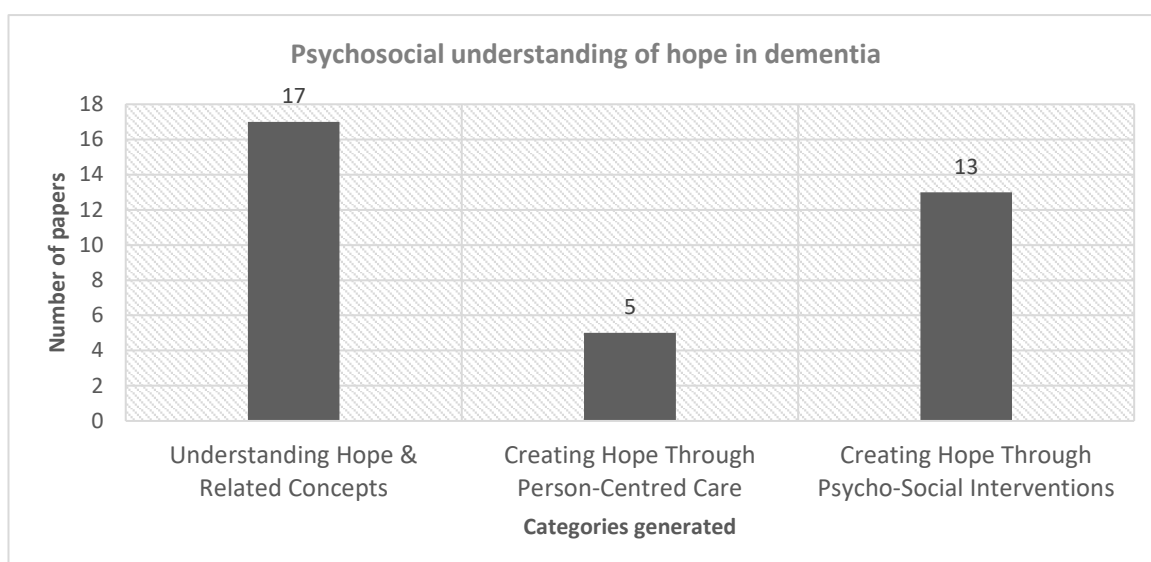


Figure 5 DelphiS literature search; Psychosocial understanding of hope

One of these (Reese, 2002) was an editorial about knowing and understanding care home residents. The other four were empirical studies which described positive changes (e.g. Kitwood, 1995) and preserved abilities such as resilience in people with dementia (e.g. Giebel et al, 2016). But none measured hope.

Thirteen papers were returned which discussed the impact of psycho-social interventions on hope and related concepts. Four were editorials, and nine empirical studies. Of the empirical studies only one (Wu & Koo, 2016) measured hope, while the others described 'increased positive affect' or 'positive effects' of interventions using different outcome measures such as well-being (Soderhamn et al, 2014) and feeling energised (Davidson et al, 2013). The study by Wu and Koo (2016) was an RCT carried out in Taiwan which measured the impact on hope (using the Herth Hope Index) of a spiritual reminiscence intervention for people with dementia. A significant improvement was seen compared with the control group.

The remaining 17 studies sought to understand hope and related concepts and these were the most relevant to this study. As the most relevant, these were again broken down into categories (see figure 6 on following page) generating three groups.

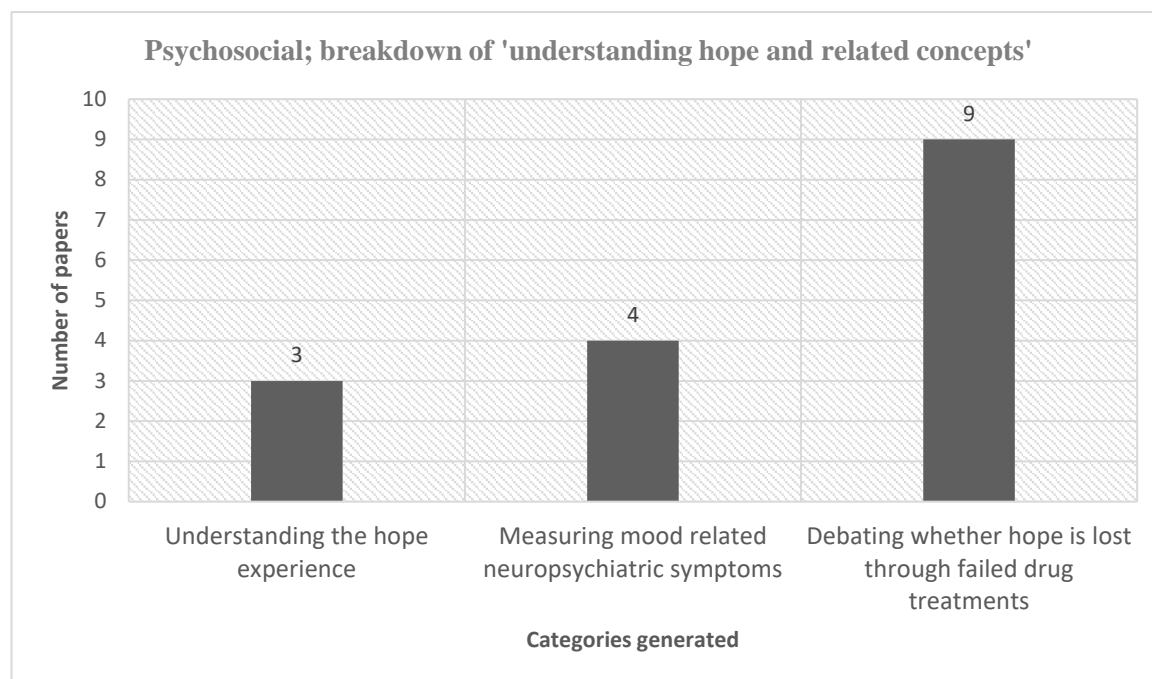


Figure 6 DelpiS literature search; Psychosocial understanding of hope; hope and related concepts

The first group contained four quantitative studies which sought to understand the prevalence of mood related neuropsychiatric symptoms in people with dementia. Teipel et al (2014) found that apathy was the most common symptom in the 27 people with dementia that they studied. Boone et al (2003) meanwhile found that people with Fronto-temporal dementia were more likely to display apathy, lack of initiative and flattened affect compared with people with Alzheimer's Disease. Thyrian et al (2015) found clinically relevant apathy in 20% of the 248 Germans with dementia studied, depression in 10%, and clinically relevant euphoria in 3%. In a larger scale study Thyrian et al (2016) meanwhile found that depression had been diagnosed in almost 17% of the 430 people with dementia in their study.

The second group contained eight editorials that described a loss of hope, and a discussion paper by Chen et al (2011) which argued that the positioning of Alzheimer's as a disease rather than as ageing creates hope for a cure. Hodges (2013) in 'hope abandoned; memantine therapy in Frontotemporal dementia', and Dimond (2010) in 'hopes dashed for Alzheimer's patients' both described disappointing results of recent drug trials that had led to a loss of hope. Vann (2013) highlighted the lack of efficacy of medications in general, as did Graham (2001) who debated whether the limited availability of medications also affected people's hope. Similar critiques of the biomedical approach were offered by Post (2001) who wondered whether unrealistic hopes



for a cure should be indulged, and by Prakash (2014) who questioned whether the stopping of cognitive enhancing medications might be seen as abandoning hope. Post (2011) and Woodward (2008) finally, emphasized that focus should not be just attached just to cure as good care was still needed.

The final group, named 'understanding hope and related concepts' contained three articles (see figure 6). All were directly relevant to the study as they involved exploration of the concept of hope in people with dementia. One was a reflective article written by a person with dementia (Graboyes, 2012). The second, a study of the experience of older people with dementia (Steeman et al, 2007), and the third a literature review of hope in early stage dementia by Cotter (2009). Articles about hope in people with dementia were found to fit within the seven categories identified in the first search. Relevant empirical studies returned from all searches were subjected to further critical appraisal which included use of CASP (2013) tools to determine their quality (see appendix A for an example of this). The seven categories generated shall now be examined in turn.

## 2.3 Defining Hope

Hope has been conceived in different ways depending on the perspective taken. It is a positive emotional state which is the opposite of hopelessness (biomedicine), a fundamental part of wellbeing (mental health Recovery approaches), a right of all people whose existence can be threatened by others (critical approaches including disability and social models), a highly individual experience that can co-exist with hopelessness (phenomenology and lived experience), a positive coping strategy connected to caring (nursing perspectives), a cognitive process which can be explained by the presence of 'agency' and 'pathway' thinking (psychological approaches) or as a natural phenomenon intertwined with faith (spiritual perspectives). An exploration of what each perspective can offer the understanding of hope in people with dementia now follows.

## 2.4 Biomedicine

### 2.4.1 Hope for a cure

Hope in people with dementia was found to be primarily associated with cure, earlier diagnosis, or of an effective pharmacological treatment being found. Many papers reported on positive results of pharmaceutical trials or hailed a new understanding of dementia through other biomedical research. Many claimed that this new knowledge brought hope, for example; 'Imaging advances give Alzheimer's patients hope' (Rowell, 2001), 'GSK-3 Inhibitors; a ray of hope for the treatment of Alzheimer's Disease?' (Martinez & Perez, 2008) and 'New drug offers better hope for Alzheimer's treatment' (Bateman, 2012). As already mentioned in all these cases hope was assumed, as none had asked people with dementia or their carers whether this made them feel more hopeful.

Some papers were less certain about efficacy, for example; 'Immunization in Alzheimer's Disease; naïve hope or realistic clinical potential?' (Foster et al, 2009); 'Stem cell therapy for Alzheimer's Disease; hype or hope?' (Liu, 2013) but these were the minority of papers recovered. No biomedical papers were returned which contained 'hope' in the title prior to 1981, and there was a trend towards increasing use of the word 'hope' over time, as can be seen in figure 7 below. Kirkman (2006), in a review of newspapers published in New Zealand has previously noted how the media tells an 'optimistic story' about scientific advances, raising people's hopes of a breakthrough, something which Moreira and Palladino (2005) have referred to as the 'regime of hope' (Moreira and Palladino, 2005). This raises the question to what extent hope is socially constructed and why and if this is a hope that people with dementia share.

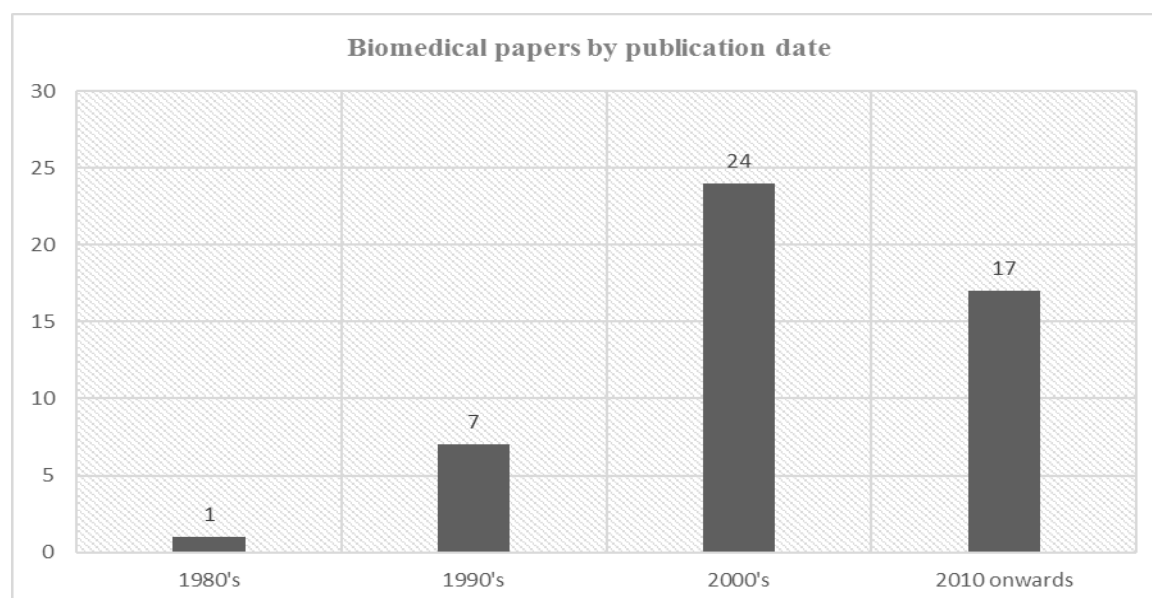


Figure 7 DelphiS literature search; biomedical papers by year of publication

Hope was perceived to be lost when biomedical science failed to deliver the anticipated breakthroughs, for example; 'Hope abandoned; memantine therapy in frontotemporal dementia' (Hodges, 2013), a phenomenon which Kitwood (1997) has referred to as; "*no cure, no help, no hope*" (Kitwood, 1997, p67).

### 2.3.2 Bioethics

Within this paradigm there is also often a focus on bioethics, which runs alongside empirical studies portraying a bleak outlook for those with dementia. Post (2001) has debated whether it is ethical to indulge hopes in therapeutic agents given their limited efficacy, and Prakash & Thacker (2014) have raised concerns that hope will be lost when these medications need to be stopped. Vann (2013), carer of a wife with dementia, has previously described the continued use of "*expensive bottles of hope*" (Vann, 2013, p525) as unjustifiable in these circumstances. Prakash & Thacker (2014) advocate hope being placed in 'more than pills'. Graham (2001), Woodward (2008) and Post (2001) offer similar critiques and emphasise that good care is still needed and should not be overlooked in the quest for a cure. Gordon & Goldstein (2001) meanwhile have debated whether it is ethical to tell a person with Alzheimer's disease their diagnosis given that it is "*perceived as a hopeless diagnosis*" (Gordon & Goldstein, 2001, p1803), while Goering (2007) has discussed the Dutch euthanasia criteria of 'unbearable and hopeless suffering' and whether this applies to people with dementia.

Relatedly and more broadly there has been debate about whether hope should be encouraged, and if 'false hope' is damaging. Much of this work relates directly to the clinical practice of doctors, and how they navigate conversations with patients who have serious illness and for whom the outlook is thought to be poor. Wilkinson (2005) describes false hope as 'cruel and destructive' affecting the patient's confidence and trust in the doctor. He states that from his experience as a clinician, for hope to be effective and believable it must be based on reality. Ruddick (1999) has similarly suggested that false hope is self-deception which may prevent people putting their affairs in order, and that failed hopes may lead to suffering. He advocates that doctors 'down-shift' patient hopes that are unrealistic. It should be noted that there is often difficulty distinguishing hope from 'false hope' in this paradigm, that the doctor's level of hope (which is tied to prognosis) is the correct amount, and that they have a moral obligation to adjust the patient's hope accordingly to match theirs.

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### 2.3.3 Neuropsychiatric symptoms

Bahro et al (1995) have described denial, avoidance, vagueness, somatization, dissociation and displacement as being among typical coping strategies of people with Alzheimer's Disease following their review of seven case studies. One person was said to be displaying denial and avoidance because he did not spontaneously mention his Alzheimer's Disease (he spoke instead of his hope that he could provide useful information for the research project). Another was said to be depressed and showing "*appropriate sadness and grief over the progression of her illness*" which was thought to be more realistic and healthy (Bahro et al, 1995, p45). Alternative ways of interpreting these findings might be to see the first person as experiencing hope and the second as hopelessness.

Another characteristic of biomedical papers when not talking about medications was that they often focussed on apathy, hopelessness and depression rather than hope. Apathy was the most common neuropsychiatric symptom found by Teipel et al (2014) who used the Neuropsychiatric Inventory (Cummings, 1997) to assess 176 German people with dementia over the age of 70. Boone et al (2003) meanwhile used the Scale for the Assessment of Negative Symptoms (Andreasen, 1989) the Positive and Negative Syndrome Scale (Kay et al, 1987), and the Emotional Blunting scale (Mendez et al, 2006) to demonstrate that apathy was three times more prevalent in people with frontotemporal dementia than those with Alzheimer's Disease in a study of 34 people. Thyrian et al (2015) meanwhile in their epidemiological study found that 19.9% of 248 community dwelling people with dementia in Germany in their study had clinically relevant apathy, and 9.9% had depression, according to the Neuropsychiatric Inventory.

### 2.3.4 Hopelessness

Lopez et al (2003) used the Consortium to Establish a registry for Alzheimer's Disease (CERAD) Behavioural Rating Scale (Tariot et al, 1995) and the Hamilton Depression Rating Scale (Hamilton, 1960) to assess a large sample (n=1155) of Americans with Alzheimer's Disease. They found that hopelessness was present in 21% participants, most commonly in people in the moderate stages of Alzheimer's. Another American study by Harwood and Sultzer (2002) entitled "*life is not worth living; hopelessness in Alzheimer's disease*" investigated the prevalence of hopelessness in a sample of 91 people with probable Alzheimer's Disease, and found using the Hamilton Depression Rating Scale (Hamilton, 1960) that hopelessness was present in 10% of the sample, being more common in people with preserved insight. This appeared to support the earlier findings of Seltzer et al (1995) in a smaller scale study of 36 people with Alzheimer's Disease, who found that

preserved insight was associated with depression. Rao et al (1997) found that nine people in their study of 125 individuals over the age of 80 expressed suicidal thoughts, and of these six (all women) had a diagnosis of either Alzheimer's or mixed dementia. There was a link between greater awareness and a wish to die in people with mixed dementia, but small numbers of people were involved, and co-morbid depression was common. In a review of the literature meanwhile Haw et al (2009) explored whether a link existed between dementia and suicidal behaviour. They found that depression was more common in the earlier stages of dementia, but people with dementia were at no greater risk of suicide than age matched controls. They did however state that there was increased risk of suicide immediately after diagnosis, and in people with preserved insight.

This raises the question whether hope is possible for people with dementia, and if their hope is more likely to be present when insight has been lost. Hope in such a situation could be seen as unrealistic or even delusional as it is based on a lack of awareness about what the future holds. Not all of the literature supports Haw et al's (2009) conclusions however. Much of their evidence came from case reports (Margo and Finkel, 1990; Rohde et al., 1995; Vega et al., 2002; Kishikawa et al., 2007) as few empirical studies have been conducted, and many that do exist have tended to contradict these findings. Draper et al (1998) for example with a sample of 148 people with Alzheimer's Disease and 24 with vascular dementia found no link between suicidal ideation and preserved insight, and Verhey et al (1993) also found no correlation between depressive symptoms and level of insight in 170 outpatients with dementia. The study by Harwood and Sultzer (2002) is also subject to methodological issues, including the fact that participants were all veterans, and 84% were male, meaning that they may not be representative of the general population.

Because neither Harwood and Sultzer (2009) nor Lopez et al (2003) compare hopelessness with that of the general population it is also not clear whether hopelessness in people with dementia is significantly different from the norm. A Finnish study interestingly found hopelessness in the general population to be occurring in approximately 11% of subjects (Haatan, 2004) suggesting that the level of hopelessness found in Harwood and Sultzer's (2002) study was no different to that of people without dementia. It should be noted that Haatan's (2004) study did not include people over 65 years of age, however and the Finnish population may not be typical of other populations, especially as Finland is known to have a high suicide rate compared with other countries (OECD, 2016). It is worth noting that Harwood and Sultzer's (2002) study also had a very small number of participants who felt hopeless (n=9) so in fact the majority did *not* feel hopeless, bringing into question their finding of 'life is not worth living'.

While these studies add to an understanding of levels of hopelessness, they do not shed light on where hopelessness comes from (other than depression), whether hopelessness changes over time, what alters these feelings, whether not being hopeless means being hopeful, and what proportion of people with dementia actually experience hope. Critically, they do not explore hope from the perspective of people with dementia.

## 2.5 Psychological Perspectives

### 2.4.1 Cognitive Psychology and Positive Psychology

Cognitive and positive psychology have perhaps added the greatest volume of work in terms of understanding hope as a concept. Positive psychology has sought to understand strengths and the experience of positive emotions, these having historically been given little attention in the literature. Myers (2000) for example found that in general such articles to be outnumbered by articles about depression and anxiety by 14-to-1. Hope is thought to be beneficial and capable of mitigating depressive symptoms (Hirsch et al, 2011) and has been seen in action through the 'placebo effect' according to Flaskas (2007) who sees it as people's ability to hope for change (Flaskas, 2007).

Snyder's (1989) cognitive model locates hope firmly within the individual's thought processes. Hope can be seen as being composed of two parts; 'agency' (a sense of optimism towards the achievement of a particular goal, or more simply 'the will') and 'pathways' (an identified way of achieving the given goal, or 'the way'). Validated tools for measuring hope have been developed, based on this concept, such as the Herth Hope Index (Herth, 1991) and Adult Trait Hope Scale (Snyder et al, 1991) and have highlighted that older people might have less hope than younger people (Bailey & Snyder, 2007) as do people with dementia (Chapman, 2011). In his doctoral study of 60 healthy older people and 60 with early-stage dementia, Chapman (2011) investigated whether stigma had an impact on hope, using the Herth Hope Index (1991), Snyder Adult Hope Scale (Snyder et al, 1991) and the Stigma Impact Scale (Fife & Wright, 2000). He found that people without dementia were considerably more hopeful, and that people with dementia had less goal-directed hope (this was not statistically significant). Stigma was not found to be relevant.

If hope is an entirely cognitive process, this unfortunately has problems when applied to people with dementia, whose cognition is impaired. If the person is not able to think creatively and flexibly they may not be able to develop ways of achieving their goals. This does not mean to say

that others could not assist with goal setting however (Bernardo, 2010). Critics of the model have also argued that pathways may not always be necessary (Martin, 2011). It is possible for example to fantasise about winning the lottery without buying a ticket, or to hope that a particular football team will win without having to actually play. She also identifies non-specific types of hope, 'transcendent' hopes which are hard to define and do not readily fit with this model, offering perhaps room still for people with dementia to be able to hope.

#### 2.4.2 Psychotherapy & Counselling Perspectives

In a review of hope literature which included psychotherapy and counselling perspectives, Bergin & Walsh, (2005) found that hope was a contributory factor in effective psychological therapy; it could assist with grief resolution (Herth, 1990), and with coping in chronic illness (Jacoby, 1993; Morse & Doberneck, 1995). Worthen & Isakson (2011) have called hope 'the anchor of the soul' and believe it is an attribute that can be cultivated, and which rises from despair and difficult situations. Lopez et al (2000) meanwhile have proposed 'hope therapy' based on Snyder's conceptualisation of hope which is summarised in Table 3 below.

Pathways	Agency
Technique 1) Providing a structure for uncovering goals	Technique 4) Looking for hopeful stories
Technique 2) coming up with clear workable goals	Technique 5) Finding the silver lining
Technique 3) Making an internal movie	

Table 3 Summary of 'Hope therapy' (Lopez et al, 2000)

They propose three techniques to help the person achieve 'pathways' thinking, or the route towards achieving a goal. The first; 'providing a structure for uncovering goals' involves assisting clients with creating a list of life domains that are important to them, ranked by importance and the level of satisfaction that it brings the person. This can be gathered by the therapist by listening to the person tell their story in narrative form. The second; creating clear workable goals involves collaboration between therapist and client in producing clear, achievable goals. The third involves mentally performing, or rehearsing the steps to achieving these goals.

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They also propose three ways of supporting the person's sense of agency; looking for hopeful stories involves a form of 'positive visualisation' (Riskind et al, 1996) where the person is asked to recall instances when they felt hopeful, through the telling of stories. Finally, 'finding the silver lining' involves optimism and assisting the person with finding positive elements in situations. These techniques assist the therapist with building the client's '*house of hope*' (Lopez et al, 2000, p145). The process has been described as '*finding*' hope, '*bonding*' (the therapist and the client building rapport based on the same level of hope), '*enhancing*' hope, and '*reminding*' of hope, which is recalling successful hope endeavours (Lopez, 2000). As yet this does not appear to have been applied to people with dementia, but the framework appears to offer a useful way of supporting hope in people who are cognitively impaired.

In a meta-analysis of 27 studies of hope enhancement strategies (none used with people with dementia) meanwhile, Weis and Speridakos (2011) have expressed scepticism that hope enhancing strategies are effective, pointing to very small effect sizes and 'probable' publication bias. They concluded that there was only modest evidence that hope enhancement strategies could increase hopefulness, in part due to the great diversity of methodologies and settings of studies to date.

While the positive role of hope dominated the psychological and cognitive literature, some writers saw hope as dysfunctional and maladaptive in certain situations. In abusive relationships for example hope for a person changing might prevent the other person from leaving. O'Hara (2011) has described despair as an ally, believing that experiencing despair is important:

*"despair has the potential to take us to the depths of ourselves, to the unconscious mire of hidden and distorted images of self and others. Put simply despair can introduce us to ourselves... despair can serve us in ways that hope cannot."* (O'Hara, 2011, p325)

O'Hara (2011) sees 'false hope' as an obstacle to be overcome, and the work of the counsellor as 'travelling' with the person through their disillusionment until 'genuine hope' can be uncovered:

*"What we often think is genuine hope is actually false hope, yet to be unmasked. Despair draws us down to the ground and strips us of our illusions, our false hopes"* (O'Hara, 2011, p325).

Dasha (2015) referred to hope as 'the enemy' which stops families of people with dementia from coming to terms with the illness. She sees moments of clarity as deceptive and providing false comfort; *"such is the deviousness of dementia: it's ability to keep hope alive while its symptoms signify only futility"* (Dasha, 2015, p49). Like the biomedical view of dementia however, she sees only loss; *"where Sam saw unchanging patterns of behaviour, I saw only the involuntary*



*maunderings of a distressed and enfeebled mind*" (Dasha, 2015, p49) and not remaining strengths. The view of the person with dementia is also noticeably absent as she presumes such? people *"psychologically absent"* (p49).

Attempting to build a bridge between the differing perspectives, Bergin & Walsh (2005) have created a framework which describes three types of 'hope work' to be used in psychotherapy with older adults. The first, 'facilitating realistic hope', focuses on challenging the person's 'unrealistic' hopes for the future, and examines whether these hopes are achievable. This again invites the questions; what is 'realistic' or 'unrealistic' hope? And does the therapist or counsellor have a right to decide? Snyder (1989) and Snyder et al (2002) meanwhile defend 'false hope', arguing that illusions can sometimes be beneficial, for example leading to better psychological adjustment (Taylor et al, 1984). The second stage of Bergin & Walsh's (2005) approach is 'the work of despair'; assisting the person with carrying out a realistic life review, facilitating despair and expressions of negative emotions and seeking resolution not change. This may not sit comfortably with practitioners accustomed to working with hope. Finally, 'surviving not thriving' involves exploring realistic hopes, shoring up coping resources, avoiding change, and focusing instead on 'containment' (Bergin & Walsh, 2005). They explain that hope is misplaced for people with dementia:

*"In the face of real physical or cognitive deficits, multiple losses, and with the likelihood of an ever reducing social network of support, hope for change may be misplaced; it is too late to reverse physical or psychological damage"* (Bergin & Walsh, 2005, p8).

The potential burden of hope meanwhile, when patients are put under pressure to behave in a positive way and to put on a brave face, is an important consideration. McLean (2011) writes that this adds additional pressure to people who are already sick and under stress. She offers a quote from breast cancer sufferer Barbara Ehrenreich's as an example; *"I hate hope. It was hammered into me constantly a few years ago when I was being treated for breast cancer: think positively!! Don't lose hope"* (Ehrenreich, 2007, p9). There are therefore perhaps a number of differences in how people cope, and how they view hope which need to be taken into account.

In the face of overwhelming social pressure (including societal pressure), people might feel compelled to hide their despair she argued, a 'conspiracy of silence', and they might feel guilty about not being able to maintain a hopeful outlook (McLean, 2011). She acknowledges the advantages which hope might bring to therapeutic interventions but concludes that overall; *"therapists should take care interfering with hope and only do so when the benefits outweigh the costs"* (McLean, 2011, p339). This is something which should be kept in mind with people with dementia and their carers, to ensure that there is not an unbalanced over emphasis on hope. This

perspective shows hope to be a complex phenomenon which needs to be better understood and considered carefully. Whether people with dementia always view hope in a positive way, or may see it as a burden is not yet known and is informed by this research.

### 2.6 Mental Health Recovery

Emerging out of social models of disability, and the service user and critical psychiatry movements, the 'recovery' approach to mental health gained popularity throughout the 1980's and 1990's and became the dominant model of care in mental health services for adults under 65 in the UK (NIMHE, 2005). This approach emphasises the pivotal role of hope in restoring meaning and purpose in people's lives and its importance in attaining the ultimate goal of 'recovery' (Mead & Copeland, 2000; Repper & Perkins, 2003; Maddock & Hallam, 2010). Recovery in this perspective does not mean cure or the absence of symptoms but an ability to live well despite severe mental illness (Anthony, 2007). Adams (2010) has pointed to the hopelessness underlying biomedical approaches that nothing can be done and that *"there can be no recovery for people with dementia"* (Adams, 2010, p2). He acknowledges the potential difficulties with the term 'recovery' but states that this does not mean that there is no place for people with dementia, especially those in the earlier stages;

*"recovery may be seen as the growth of the person with dementia, even though they have the condition. In this respect it is likely that people in the early part of their condition are most likely to appreciate scope for personal adaptation, hope-inspiring relationships, and access and social inclusion"* (Adams, 2010, p3).

Hope is central to mental health recovery (Adams & Partree, 1998; Jacobson & Greenley, 2001; Corrigan, 2004; Adams, 2010), and a top priority to service users (DBSA, 2002; DBSA, 2004; DBSA 2006 all in Stotland et al, 2008). Hope is seen as applicable to everyone, with recovery 'open to all' (Roberts & Wolfson, 2004). Repper and Perkins (2008) see hope as essential to recovery:

*"without hope – a vision of possibility – then recovery is impossible. If you cannot see any possibility of living a decent and valued life then there is no reason to do anything, no reason to get up in the morning, no reason to stay alive"* (Repper & Perkins, 2008, p6).

Hope therefore is seen as a motivator, and is also thought to also help with positive adaptation to stress and build resilience (Ong et al, 2006). Links between recovery and 'living well with

dementia' (DoH, 2009) seem possible. Several writers have written about recovery and whether it could be a useful concept for people with dementia, identifying many commonalities with person-centred care (Woods, 2007; Adams, 2010; Martin, 2009; Hill et al, 2010; Gavan, 2011). The recovery concept has still to be fully applied to people with dementia however, and a study by Marshall et al (2015) was the only published study found. This randomised controlled trial demonstrated improvement in quality of life in people attending a ten week 'living well with dementia group' which had incorporated recovery principles into its design.

Unfortunately, as Hill et al (2010) point out, early attempts to make recovery 'open to all' during a documentary (BBC Panorama, 2004) were met with considerable resistance. The Alzheimer's Society (2004) responded on behalf of angered carers calling its helplines, highlighting what they perceived to be a lack of awareness about the progressive nature of dementia. It adopted the biomedical standpoint; *"the care needs of people with Alzheimer's and other dementias are the result of a physical disease of the brain for which there is currently no cure"* (Alzheimer's Society, 2004) and arguably stifled the debate. This demonstrates how caution is needed when using terminology such as 'hope' and 'recovery' that people may not be familiar with and which is open to misinterpretation.

In defence of the recovery approaches, Gavan (2011) has reiterated that hope should not be bound entirely to the concept of cure in dementia care, and that a broader understanding is required. She has postulated that hope might be fostered for people with dementia through empowerment (enabling people to make choices and enhance positive aspects in their lives), assessing people's strengths, and through 'hope-inspiring relationships' (Gavan, 2011). Martin (2009) has spoken approvingly such 'hope-inspired relationships' (Repper & Perkins, 2003) and makes comparisons with hope in Kitwood's work, as does Gavan (2011), and also Woods (2007) who emphasises that hope was one of Kitwood's 'four global states in his earlier work:

*"The fourth state is that of hope. In other words, a person still retains a confidence that some security will remain even when so many things are changing, both outside and within. There is a freedom from the anxiety that pervades if many basic needs are not met. Hope is, preeminently, a sense that the future will be, in some way, 'good'. In many respects the dementia sufferer has little ground for hope; this is doubly the case in the light of the pessimism of prevailing ideology. To retain hope in the face of severe dementia is thus to have overcome huge obstacles. It is worth noting that hope, in the sense used here, need not be tied to specific scenarios about the future, and so require complex cognitive skill. It is nearer to the psychoanalytic concept of 'basic trust'. When*

*this is present a person can relax and the state of the 'free-child' (available to all of us but often kept right in the background) can prevail"* (Kitwood & Bredin, 1992, p283-284).

Cutcliffe & Barker (2002) have pointed out that people cannot be 'forced' to be hopeful and that the goal of mental health professionals should be hope inspiration, through unconditional acceptance, tolerance and understanding. The importance of mental health workers 'holding hope' for people who are mentally ill during times when they are unable to carry it themselves has been described by Darlington and Bland (1999) in interviews with six experienced mental health workers, although this concept has not yet been fully applied to people with dementia. Hill et al (2010) in an article about the applicability of recovery to old age psychiatry and people with dementia speculate whether the approach might be problematic for clinicians; *"Holding hope in such circumstances may seem naive or mistaken and thus a challenge to clinicians trying to uphold recovery or person centred values in older people's services"* (Hill et al, 2010, p292). Woods (2007) points out that two studies demonstrated promise as both studies have shown that the level of hope present in care staff was closely correlated with the quality of life of the people with dementia who they worked with, indicating that 'holding hope' might be both possible, and therapeutic. Zimmerman et al (2005) used reports by care staff and observational measures to evaluate 421 residents with dementia and found that those with staff with dementia-sensitive attitudes, especially hope, had higher quality of life scores. Spector & Orrell (2006) meanwhile found similar results with 76 dyads of people with dementia and care home staff from nine different care homes.

Narrative is a commonly used methodology in this approach, and many people have written about the importance of hope to them and its role in their recovery from schizophrenia and other forms of enduring mental illness. Patricia Deegan for example has written extensively about her experiences of institutionalisation, and in 'the conspiracy of hope' (Deegan, 1996), an address to an Australian mental health conference, she described how hope seemed forbidden, even dangerous for someone with her diagnosis. Parallels with dementia are clear:

*"I love the word conspiracy. It comes from the Latin "conspirare" which means to breath the spirit together. What is the spirit we are breathing together here today? It is a spirit of hope. Both individually and collectively we have refused to succumb to the images of despair that so often are associated with mental illness. We are a conspiracy of hope and we are pressing back against the strong tide of oppression which for centuries has been the legacy of those of us who are labeled with mental illness"* (Deegan, 1996, p2).

Deegan's (1996) writing is often reminiscent of Kitwood's (1997) work on 'personhood' and 'malignant social psychology' as can be seen here, particularly where she describes environments which are toxic to recovery:

*"We are here to witness that people who have been diagnosed with mental illness are not things, are not objects to be acted upon, are not animals or subhuman life forms. We share in the certainty that people labeled with mental illness are first and above all, human beings. Our lives are precious and are of infinite value"... "If we plant a seed in a desert and it fails to grow, do we ask, "What is wrong with the seed?" No. The real conspiracy lays in this: to look at the environment around the seed and to ask, "what must change in this environment such that the seed can grow?" The real conspiracy that we are participating in here today is to stop saying what's wrong with psychiatric survivors and to start asking: "How do we create hope filled, humanized environments and relationships in which people can grow?""* (Deegan, 1996, p2.)

Recently people with dementia have also begun telling their own story, including their stories of hope, and many have echoes with the narrative accounts of people with other forms of mental illness. Christine Brydon (2005) in her book 'Dancing with dementia; my story of living positively with dementia' for example challenged the idea that hopelessness was an inevitable and enduring part of dementia. She frequently displayed a determination and zest for life despite her diagnosis which she discusses frequently, as she does her choice to be a 'survivor', adjusting and adapting to new symptoms and losses like steps in a dance. In an article Graboys (2012) speaks eloquently of his hope:

*"there is one aspect of the self that even my disease cannot touch and that is the soul...and that is where hope lives; not a naive hope that I will, by some miracle, have my former self restored, but hope that tomorrow, and the day after, can still be days from which a measure of joy and meaning can be derived"* (Graboys, 2012, p1359).

Basting's (2003) analysis of three autobiographies by younger people with dementia (McGowin, 1993; Davis, 1989; and Henderson, 1998) found that the act of telling one's story could be an important source of hope for people with dementia, especially when this was seen as a way of helping others. Davis's (1989) felt that his ability to communicate, and write was akin to a gift:

*"Why has God left me this little window of ability? ...perhaps it happened so that I can be the voice for the voiceless people who suffer from this devastating disease....perhaps I can still communicate so that I can give new hope and assurance to those faithful Christians whose former emotional feelings and blessings are being washed away by the*

*start of the disease, and who are in spiritual despair because they are unable to understand what is happening to them” (Davis, 1989, p21-22).*

An ethnographic analysis by Page & Keady (2010) of twelve autobiographies written by people with dementia did not mention hope, but did touch on hopelessness experienced by three people including that of Scheider (2006) who used to work as a fireman. He said of dementia:

*“It does not ask permission. It can change your language, steal any words it wants to and give you profanity in their place. It can cast a spell of fear and hopelessness on many of its victims. It is not content to slowly kill you. It wants to torture, humiliate, embarrass and confine you. It refuses to ease your suffering by allowing you a quick death. It not only delights at abusing its victim, it also wants to torture their loved ones” (Scheider, 2006, p47).*

Meanwhile action based research by Pipon-Young et al (2012) found that the act of creating information leaflets for what? brought people with dementia hope. Many participants in the study also spoke in more general terms of a need to retain hope, and to remain hopeful for the time they had left. Information which was written by peers (rather than professionals) was more highly valued and was said to foster hope and build inner resilience, both key recovery concepts. The researchers concluded that there may be a need to think about dementia within a Recovery framework in order to provide services which engender hope.

Recovery approaches appear to offer a great deal in terms of understanding what hope looks like to people with mental illness, where hope comes from, and what might help or hinder it.

Recovery approaches have been criticised for their perceived lack of evidence base, their data being drawn primarily from narratives which are seen by some researchers as being positioned low down in the hierarchy of evidence. However it could be argued that such hierarchies are a biomedical construction and that such qualitative data is essential to effectively understand the phenomenon of recovery which is a highly personal and individual construct. Roberts (2000) for example has critiqued the impact that evidence based medicine has had on stories and narrative; *“thus, the evidence of testimony or opinion has been identified as dirt on the lens of science, which EBM has been created to remove, and its methods are such as to eliminate the complexity of individual variation” (Roberts, 2000, p432).*

A further criticism of this approach might be that there does appear to be considerable publication bias in terms of the narratives of people with dementia which are within the public domain. A conspicuously large number of authors are clearly extremely intelligent, articulate, and successful people and are also often much younger than average. Christine Brydon used to work

for the prime minister's office for example; Thomas Graboys is a cardiologist and professor of medicine, while Cary Henderson is a professor of history. Critics could argue therefore that such narratives may not be representative of the majority of people with dementia and do not represent their experience. Ryan et al (2009) however in their analysis of twelve memoirs written by people with dementia have acknowledged that the authors of each were 'exceptional people' but dispute that all held positions of privilege, reporting diversity in the author's backgrounds. It does however provide a foundation for further analysis of hope in younger people with dementia.

## 2.7 Critical approaches including disability and social models

With contributions from sociology, social psychology, social work and gerontology as well as connections to recovery approaches, disability research in dementia has focused on how environments and society, not just cognitive impairment, disable and oppress people with dementia. Most of the work is theoretical rather than empirical in nature, but it has greatly added to a broader understanding of the experience of dementia. Beard and Fox (2008) have spoken of the historical marginalisation of people with dementia in research, and lack of interest in their perspective. They attribute this '*social disenfranchisement*' (Beard & Fox, 2008, p1510) to barriers people experience including; their family's difficulty in adjusting to their illness; the 'demonization' of dementia to support public interest in research; and in 'scientific arenas' by the reductionism and objectification implicit in biomedical research. This 'demonization' of dementia is also mentioned by Moser (2008) in 'making Alzheimer's disease matter', who describes how statistics are used to invoke "*future tides, avalanches and crises in care systems and public health budgets*" (Moser, 2008, p100), calling organisations and governments to action against dementia. But at what cost? It has been argued that biomedical constructions of dementia as a feared, hopeless and incurable medical condition (Lyman, 1989; Bond, 1992; Kitwood & Bredin, 1992; Kitwood, 1997) create great stigma for people with dementia, which can be amplified through messages in the media (Herskovitz, 1995; Kirkman, 2006). Behuniak's (2011) chilling analysis concludes that people with dementia are even stigmatised to the extent of being represented as zombies:

*"the frightening celluloid images of fictional characters called zombies have leaked into the popular and scholarly discourse about real people who have Alzheimer's disease, constructing them as animated corpses and their disease as a terrifying threat to the social order. The zombie-AD patient connection is not therefore a case of art imitating*

*life, but of a far more complex cultural relationship. The zombie instils fear by drawing from cultural anxieties, and then reflecting them back to the population that in turn breaths life and strength into them by applying this fictional representation to social realities. In this way, the social construction of those with AD as zombies generates not only the negative stereotypes and stigma associated with people constructed as 'other', but also the emotional responses of disgust and utter terror (cf. Scholl and Sabat 2008). It is this politics of revulsion and fear that directly infuses the discourse about AD and shapes it" (Behuniak, 2011, p72.)*

Such a discourse might justify marginalisation of people with dementia, and leave little room for hope. Innes (2002) has highlighted the emphasis on progressive decline and hopelessness in the dementia narrative which leads to dementia being seen as a 'living death'. Behuniak (2011) hints that this might lead to the perceived acceptability of euthanasia; *"the zombie's overwhelming hopelessness that makes death a preferred alternative than continued existence"* (Behuniak, 2011, p72).

O'Sullivan et al (2014) echoes these concerns, and offers some possible solutions:

*"dementia is not necessarily something to be afraid of; it is how we imagine it and what we make of it that is intimidating. We must all assume responsibility for changing attitudes because if we wait for knowledge and understanding shaped solely by medical science then we are restricting people with dementia to a narrow vision of hope for the future"* (O'Sullivan, et al, 2014, p12).

Harris & Keady (2008) have also spoken of the collective responsibility to change to a more positive discourse, including concepts such as 'wisdom', 'resilience', and 'successful aging', opening the door perhaps to an understanding of dementia built on strengths, and allowing space for hope. In 'positive long-term changes' Kitwood (1995) has spoken of such strengths, describing personal growth in people with dementia. Qualities such as; warmth, affection, truthfulness, spontaneity, concern for others, friendship and sense of humour which can be seen, but are rarely discussed if at all in literature. Innes (2002) similarly argues that *"if personhood is maintained, a sense of social confidence, worth, agency and hope will have been preserved for the person with dementia"* (Innes, 2002, p494). O'Sullivan et al, (2013) meanwhile has advocated a rights based approach; *"people with dementia have the right to live life to the best of their abilities"* (O'Sullivan et al, 2014, p11) and to *"hope and to dream of living a satisfying and healthy life"* (O'Sullivan et al, 2014, p12).



Encouragingly, as discussed earlier (section 2.4.1) Chapman's (2011) study found that stigma was not found to be a mediating factor between hope and quality of life. The choice of methodology may have been a factor (it has been argued that the hope scales used may not be sensitive when used with older people) but it may also be that people with dementia in the study had learned to adapt to and cope with the difficulties they encountered. Support for this comes from previous studies with qualitative methodology which found that people with dementia actively resist social stigmatisation and exclusion and renegotiate their everyday lives, building collective identities instead (Beard & Fox, 2008; Beard et al, 2009; O'Sullivan et al, 2014). Further research is still needed to investigate how people with dementia can be supported to resist disempowerment and find hope.

This contrasts not just with biomedical ideas of 'no hope' but also perhaps with the concepts of 'false hope' and 'unrealistic hope' seen in the biomedical, nursing, and psychoanalytical literature where hope is not seen in an exclusively positive way. It could be counter argued that disability perspectives in general fail to take account of the practical, ethical and moral complexities of healthcare, in particular duties of staff towards non-maleficence, should hope prove damaging. Perhaps a useful way to proceed therefore is to hear the voices of people with dementia about hope and 'false hope' and whether they view hope as negative or positive. It is this lived experience of hope in dementia which shall therefore be discussed next.

## **2.8 Lived experience**

Researchers investigating the lived, or subjective experience of dementia have added a significant amount of rich information to the understanding of hope in people with dementia. Many studies have offered insights into what people with dementia hope for. Clare (2002) in a UK based study for example interviewed twelve people with dementia and their partners (average age 71) in order to understand how they coped with their diagnosis. She found that hope could sometimes take the form of the person hoping that they did not really have Alzheimer's, hope for improvement in memory through cognitive enhancing medication, or hope of a cure (suggesting perhaps the influence of biomedical perspectives on participants). Critics might argue that these sorts of hopes represent denial, or 'false hope', but Clare (2002) found that the hope experience was much more complex:

*“Participants needed to arrive at a realistic view of what could achieve for them, and what their own efforts could contribute. They needed to find a balance between accepting help from others and becoming too dependent. When trying to obtain information, they needed to achieve a balance between finding out what they wanted to know and learning many horrifying details that were too upsetting to bear. They needed to find a balance between the negative aspects of Alzheimer’s and the ways in which they could learn from it and understand themselves better. Essentially this need to achieve equilibrium could be summed up as needing to find a balance between hope and despair. Given the progressive nature of Alzheimer’s, the point of equilibrium could never be regarded as fixed, but would be continually shifting, requiring an ongoing process of adjustment. Achieving and maintaining equilibrium could be viewed as one of the key adaptive tasks that participants faced” (Clare, 2002, p146).*

MacQuarrie (2005) in her longitudinal study of the lived experience of fourteen people with dementia living in Canada also found evidence of acceptance and denial occurring together, concluding that this was a form of active coping;

*“participants simultaneously acknowledged and resisted aspects of their disease in order to maintain agency in the face of cognitive losses. Acknowledgement was expressed through the themes involving acceptance of the disease and its symptoms, expression of feelings about the disease, and strategies to cope with the symptoms” (MacQuarrie, 2005; p430).*

Some hopes could be realistic and achievable, such as those of one participant who said; *“My best hope is to be able to live more to be able to continue with my friendships I guess”* (MacQuarrie, 2005, p435) while an older person with Alzheimer’s Disease in Sørensen et al’s (2008) study hoped simply to be able read more books. Clare et al (2008a) found that whether hope was realistic did not necessarily matter to people with dementia living in residential care who took part in a series of unstructured conversations, it was the hope itself which was sustaining. In another Canadian study MacRae (2008) carried out semi-structured interviews with eight people with early stage dementia and discovered that hope could be a resource that people drew on to find strength. The use of strategies such as humour were common, and people with dementia created hope for themselves, not necessarily accepting a helpless ‘victim’ role. In fact many people reported being frustrated with negativity and hopelessness that other people associated with Alzheimer’s Disease (MacRae, 2008). One of Clare’s (2002) participants spoke of fighting back; *“we’ll fight as long as we can”* (Clare, 2002, p1025) and of how contributing to research brought him hope. People with dementia in Beard and Fox’s (2008) study which took place in

California, USA also reported that taking part in research made them feel that they were doing something proactive and which helped others. But when their access to studies was denied this could lead to a loss of hope:

*“many respondents suffered angst over not having access to studies they hoped could help them or being excluded due to previous medication usage. Inclusion criteria for basic research also highlight the staged decline of Alzheimer’s as individuals found themselves too impaired to participate in a given study”* (Beard & Fox, 2008, p1515).

Genoe (2009) in her doctoral study (see also Genoe & Dupuis, 2014) interviewed four Canadian participants to understand the role of leisure in their experience of dementia, and found that people struggled with the changes they experienced but found ways to tackle life with dementia and to live with hope, experiencing personal growth and development in the process. Their experience of hope was often fluid, hope being weakened initially by their dementia diagnosis, but as they reconciled thoughts around this they were able to develop a positive attitude (Genoe, 2009; Genoe & Dupuis, 2014). Preston et al (2007) also remarked on the importance of ‘being positive’ to twelve people with dementia living in the south of England, finding that people often felt ‘challenged’ rather than depressed by their illness, and could experience positive change. In Phinney et al (2007) one Canadian participant spoke of being ‘glad to be alive’ while others spoke of enjoying their lives (Phinney, 2007; Radbourne, 2008). Wolverson et al (2010), the publication of Radbourne’s (2008) doctoral research, described the experiences of ten older people with early stage dementia recruited from memory clinics in the UK. They were asked during semi-structured interviews about their hope, its personal meaning, their personal resources, and barriers and facilitators of hope. Following Interpretive Phenomenological Analysis, it was found that participants perceived hope as integral to living and a key theme was ‘live in hope or die in despair’. Their hope was often learned during childhood and was innate. Only one participant described her desire for a cure which she acknowledged was a ‘false hope’. The authors highlighted what they felt was a ‘paucity of literature’ in applying hope theory to dementia care which they felt reflected the widespread belief that age and dependency combined with impaired cognition are hope-hindering experiences.

Other studies found different experiences however and hope was not always either present or positive. One older person with dementia described his experience as *“hellish”* in a Canadian study by Hulko, 2009, p136) and participants in Kiyak’s (1988) study were said to have used less problem-focused coping and hopefulness than emotion-focused strategies such as being angry, bitter or resentful. A study of the subjective experience of younger people with dementia living in

America by Harris (2002) suggested that younger people experience marked hopelessness and loss due to their social situation, demonstrated by one participant in her 40s:

*“each day is filled with such powerlessness, such despair for what I have lost...an older person with AD does not bankrupt their young family; wipe out all college funds with nursing home costs. I can handle that I will lose my life, but that my children’s mother will die and leave them is unbearable to me. To know that my husband’s life will be put on hold for years, in his prime”* (Harris, 2002, p12).

This suggests that further research looking at social context, especially the concept of burden, might be useful to better understand the context of hope. Another study, this time by Svanström and Dahlberg (2004) interviewed couples living in the community in Gothenberg, Sweden, and using a phenomenological approach concluded that living with dementia was a ‘lost existence’ for both parties:

*“those interviewed perceive their existence as characterized by hopelessness, indicating that it is difficult to think ahead. Persons with dementia cannot look forward or backward in time; they live in the present. When it is at its worst, it is hard to even talk about it. A person with dementia gives his view on his life and his future: (pwd) “Well, actually I have no aims anymore. Life is over”* (Svanström and Dahlberg, 2004, p679-680).

This was echoed in a study by Robinson et al (2005) who interviewed older couples in North London, UK, and found that all felt hopeless at the point of diagnosis. Aminzadeh et al (2007) found that some of the 30 Canadian couples they interviewed shortly after diagnosis appeared to be in denial, or experienced grief, but crucially some also displayed positive coping. They located these experiences within a stage model of emotional reaction to the diagnosis, suggesting that these experiences may be transitory and part of a move towards adjustment.

De Witt et al (2010) found that hopes were not necessarily for positive events and that some of the eight Canadian older people with dementia interviewed hoped for death; *“being worse was feared more than death, and some of the women hoped for death before their illness progressed”* (De Witt et al, 2010, p1703). The extent to which people with dementia hope for death is unknown, but a UK study by Williams et al (2007) found that almost 60% of the general public who returned their questionnaires (response rate not disclosed) believed that assisted-suicide should be permitted for people with severe dementia, and 55% thought it should be permitted for people with mild or moderate dementia. Hertough et al (2007) in a review of Dutch legal cases, reported that requests for assisted-suicide from people with late-onset Alzheimer’s Disease are

virtually unheard of however, and speculate that fear of dementia (rather than the actual lived experience) may influence people's perceptions about whether life is worth living. As already mentioned negative media messages about dementia (Kirkman, 2006) may contribute to the continued perception of people with dementia as 'empty shells.' Researchers of the lived experience of dementia reject this view, and Bryden (2005) has called it a 'toxic lie'. Quality of life therefore appears to be best understood as a subjective, rather than objective experience (Bond and Corner, 2004) and requires further exploration of the lived experience of dementia (Hertough et al, 2007).

## 2.9 Nursing perspectives

Hope within the nursing research can be seen as a positive coping strategy in response to poor health, with hope promotion being integral to the nursing role (Morse & Penrod, 1999; Miller, 2007; Tutton et al, 2009). Much of the earlier nursing work on hope discussed the value of hope and how it might be enhanced. Herth and Cutcliffe (2002) for example asserted; *"research supports that the clinician is an instrument through which hope can be assessed and administered"* (Herth & Cutcliffe, 2002, p977). Studies also tended to be of a reflective or theoretical nature (Buehler, 1975; Dubree & Vogelpohl, 1980; Kim, 1989; Yates, 1993; Douville, 1994; Wilkinson, 1996; Cutcliffe, 1998; Castledine, 2000; Penson, 2000). This has attracted criticism from Lipscombe (2007) who has pointed to their failure to conform to the 'hierarchy of evidence' (Page & Meeraabeau, 2004) and concludes that nurses should distance themselves from the hope which *"cannot be situated within a sustainable scientific theory"* (Lipscombe, 2007, p335). As mentioned previously the nature of the subject being studied may not lend itself to randomised controlled trials however.

There is however a growing body of original research which has demonstrated that hope is present, and greatly valued by older people (Zorn, 1997) and those with chronic (Fox, 1999; Rustøen et al, 2003) life threatening (Felder, 2004; Schjolberg et al, 2011) and terminal illness (Buckley & Herth, 2004; Duggleby & Wright, 2004; Johnson, 2007; Duggleby & Wright, 2005; Elliott & Oliver, 2009; Olsson et al, 2011). Some studies have even unexpectedly shown that when quantitatively measured, hope can be higher than average in these groups (Zorn, 1997; Ebright & Lyon, 2002; Rustøen et al, 2003; Felder, 2004; Schjolberg et al, 2011).

Many nursing studies have examined the efficacy of psycho-social interventions to people with dementia, but only one study was found which had explicitly used hope as an outcome measure. It is unclear exactly why this is, but it is possible that this is due to the dominance of the cognitive model of hope within the nursing perspective; *“the defining attributes of hope suggest the necessity of cognitive functioning”* (Forbes, 1994, p9). The study, a Taiwanese randomised controlled trial by Wu & Koo (2016), showed that levels of hope in older people with mild and moderate dementia experience could be significantly increased through a six-week spiritual reminiscence intervention. Scores on the Herth Hope Index (Herth, 1991) were noticeably similar pre-intervention to those found by Chapman (2011).

Rustøen et al (2003) meanwhile conducted a large scale study of 4000 randomly selected Norwegians who were sent questionnaires and a Herth Hope Index to complete. The response rate was 49% and full data was collected from n=1825 people. They found that several sociodemographic and health-related variables were significantly associated with hope; older age, male gender, being divorced or widowed, being retired or unemployed, and having a chronic illness (particularly mental health problems, gastrointestinal disorders, and having had a stroke). As dementia is associated with many of these variables, it could be that the sociodemographic profile of people with dementia (rather than the dementia itself) is contributing to their low levels of hope.

Furthermore, older people and those who are terminally ill may experience hope differently, with less future orientated hope (Zorn, 1997), more short-term hope (Gibson & Gorman, 2012) and greater incidence of experiencing hope for others rather than oneself (Duggleby & Wright, 2004). Tools currently used to measure hope place emphasis on personal goals, including those in the long-term, so may not be sensitive to the type of hope that people with dementia experience. Interestingly it was the goal-related hope scores which were particularly low for this group in Chapman’s (2011) study, supporting this hypothesis.

Herth’s (1993) study looked at the hope of 60 older people living in a variety of settings in Illinois, USA, and found that cognitive impairment was a key inhibitor of hope among participants. It is not clear from the study whether any of the participants were actually cognitively impaired, or whether they just worried that they were, but fear appeared a mediating factor in the loss of hope, presenting the intriguing possibility that it is the meaning attached to memory loss which erodes hope, rather than the cognitive impairment itself.

Participants expressed that the fear of *“losing one’s mind”* and the inability to remember things diminishes hope. One participant commented, *“I’d lose hope if my mind slipped”* and *“When I forget things, my hope diminishes another inch.”* (Herth, 1993, p147).

This once again hints at a link with stigmatisation, and it is possible that Chapman's study did not fully capture self-stigmatisation when the level of stigma people with dementia experience was measured. Fear has also been mentioned elsewhere in psychological studies, where from a cognitive and neurological point of view the presence of fear appears to directly preclude the experience of hope; *"hope, in contrast, as a secondary emotion, involves cognitive activity, which requires anticipation and the search for new ideas and thus is based on complex processes of creativity and flexibility. Therefore, hope is often preceded and inhibited by spontaneous, automatically activated and faster fear"* (Jarymowicz & Bar-Tal, 2006, p367). This means that there may actually be a physical barrier in the brain to people with dementia experiencing hope when fear of their illness or their symptoms is present.

Interestingly Fredrickson and Branigan (2005) in a study of 104 college students found that the opposite could also be true. Students who watched films that induced positive emotions (amusement or contentment) showed superior scores on tests of cognitive faculties such as attention compared with those who watched neutral, or anger, or anxiety inducing films. This raises the possibility that improved functioning may be possible for people with dementia who experience positive emotions such as humour, and perhaps hope.

Emphasis in nursing approaches is often heavily placed on better understanding what helps and what hinders patient and carers hopes. Insights have been gained in two key ways; firstly by interviewing nurses and asking them how they support hope in these groups, and secondly; by interviewing patients themselves and asking what helps and what does not. Studies of nurses have found that hope is often seen as an inner strength (Benzein, 1998) which can be influenced by nursing actions and interventions such as listening (Turner & Stokes, 2006; Benzein, 1998) affirming worth (Herth, 1995) being self-aware (Herth, 1995) working in partnership (Herth, 1995) building trust (Turner & Stokes, 2006) and working holistically (Herth, 1995). Instilling 'realistic hope' was felt to be important in order to avoid giving 'false hope' (Tutton et al, 2012; Hockley, 1993; Yates, 1993). Other nursing researchers have noted that 'unrealistic hope' may be a valid way of coping however and express the view that it should not be interfered with (Johnson, 2007). Nurses who worked with cognitively impaired adult were found to also support hope through using humanistic principles and interpersonal relatedness, but key differences were that they also were said to use 'pragmatic knowledge' and organisational skills to create hope (Cutcliffe & Grant, 2001). The number of nurses interviewed was small however (n=5) and they worked on the same ward, and were thus presumably part of the same working culture. The mechanism by which these two techniques create hope and how these differ from the tasks generally listed in nurse's job descriptions is also unclear, and Cutcliffe & Grant (2001) himself

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ultimately concluded that hope could not be separated from helping and from the fundamentals of nursing.

Another key problem with these studies (which they have in common with biomedical and psychological approaches) is that they tend to position nurses as the experts into what builds hope in others, rather than asking patients themselves, and they therefore ignore the biases inherent in the nursing perspective, which often includes a bias towards thinking that nurses have the more realistic view. This is the antithesis of recovery approaches which take great pains to reduce power inequities and professionally dominated views of the world. These types of studies from a methodological point of view provide less rich information as they tend to describe what happens; what nurses do, without commenting on its appropriateness or efficacy. In the case of Cutcliffe & Grant's (2001) study there is no discussion about whether nurses actually felt hope was relevant, which it would have been interesting as the word 'hope' is tellingly absent from participant's discussions in a way that it is not in studies of people with other illnesses.

This does not truly answer the question as to whether nurses working with people with cognitive impairment believe hope is possible, nor has this been done elsewhere in the literature. There is evidence that healthcare professionals can find it more difficult to convey hope with particular illnesses such as motor neurone disease, because prospects are perceived to be poorer, progression more rapid and disability greater than in multiple sclerosis (Carter et al, 1998). Almost 5% of the 317 participants in this study in fact felt that they could not promote hope, with stark messages for nurses working with people with dementia, given the similar nature of both illnesses. This trend was not seen in hospice staff however, suggesting that perhaps specialist training and support can alter how hopeful staff feel, and how much hope they can therefore convey to others.

Werezak and Stewart (2002) in their interviews with six people with early-stage dementia (ages 61-79 years) found that maintaining hope was important to participants. One person expressly hoped that their diagnosis was wrong and this maintained his sense of hope, even though in many respects they knew this was unrealistic: *"in my mind I still feel like I'm going to beat this, but then after reading about it I know there's no cure...I still have a bit of hope that it may not be actually Alzheimer's"* (Werezak & Stewart, 2002, p79).

Other people in Phinney et al's (2007) Canadian study of meaningful activity hoped that they would live longer so that they could continue to enjoy life:

*"Maggie spoke often of how she was 'glad to be alive', and in speaking of her future said, 'I hope we are able to do things and not just feel sorry for ourselves. I'd like to live*



*to be 100.’ She recognized that the Alzheimer’s would only get worse, but mostly she turned away from her fears of the future toward activities that brought her pleasure. By finding enjoyable things to do, she was able to say ‘I’m still alive and that’s (little laugh) you know, “So what? It’s not so bad. I can still get along.”’ Christina was another participant who spoke of activity as a way to enjoy her life despite having a devastating illness. ‘I hope that I could stay at this stage (of the disease) for as long as possible because I am enjoying myself’ (Phinney et al, 2007, p388).*

In a review of the dementia literature Phinney (2008) has noted that people with dementia often struggle to remain hopeful, but that it can help them to get through challenging situations. She notes that although many people’s hopes are centred on a cure or a medication which can halt the disease process hope can be much broader than this:

*“hope does not stop there. Even when people recognise the inevitability of their situation, some still face their future with a certain hopefulness that helps them feel more encouraged and less despairing. For example, more than anything, one person hoped that he would remain at home in the care of his family until the end, while another clung to the hope that she would continue to experience simple joys in her life as her cognitive capacities failed” (Phinney, 2008, p43.)*

A concept analysis of hope in early-stage dementia by Cotter (2009) found that there was little coverage of hope in this group in the literature, but that hope appeared to be central to adjustment and that hope could be seen in people even in the moderate to late stages of dementia. Hope could occur in response to the person’s awareness of their diagnosis, and could lead to positive changes including opportunities for growth. As with the wider population (Giske & Artinian, 2007) carers of people with dementia coped with hopelessness by ‘renewing’ their hope, countering attempts to reduce it (Duggleby et al, 2009).

Nursing research has placed a great deal of emphasis on changing people’s levels of hope, by either increasing hope, or reducing it in order to make hope ‘realistic’. As previously mentioned, other approaches do not always share the view that altering hope is either possible, or something that nurses have a right to do. Again, perhaps the best course of action is to ask people with dementia what they think about attempts to alter their level of hope, and whether this is acceptable to them (which has been done in this study). Despite disagreements about how best to proceed, it cannot be denied that nursing researchers have greatly deepened and enriched our understanding of hope. The approach also has considerable pragmatic benefits. Nurses are well

placed to work with people's hope, and in terms of generating information which will make a difference in practice the nursing approach has been invaluable. Perhaps therefore in terms of understanding how nurses might work with the hope of people with dementia it has yet to realise its full potential.

### 2.10 Spirituality

Hope emerged as a key theme in interviews with people with dementia about spirituality (Snyder, 1999; Bell & Troxel, 2001; Snyder, 2003; Beucher & Grando, 2009; Dalby et al, 2011). Studies have shown that some people with dementia may hope for an afterlife (Snyder, 2003; Stuckey, 2003; Dalby et al, 2011) or that God will hear (Powers & Watson, 2011) and help with their symptoms (Beucher & Grando, 2009). Hope is often described in a future orientated way, for example in hope for being released from suffering (Snyder, 2003). Hope has however also been described as being grounded in the present, in each day to day moment (Stuckey et al, 2002; Phinney 2008; Dalby et al, 2011).

McCurdy (1998) has spoken of the centrality of hope to Judaism and Christianity: *"God is a source of hope, one who is creator, healer, and redeemer of human beings in (and despite) their ills and evils, their helplessness and hopelessness"* (McCurdy, 1998, p83). MacKinlay (2012) similarly found that for Australian, non-aboriginal people with dementia living in care facilities spirituality and meaning in life could help them find hope. Beucher and Grando (2009) also found that personal faith, prayer, and connection to the church and family helped fifteen people living in Arkansas, USA with early-stage Alzheimer's Disease keep a positive attitude as they lived with the illness. It should be noted that participants came from within the 'Bible Belt' and so this may have affected how hope was seen. Prayer and a belief in God helped people to gain acceptance and to relieve worry:

*"prayer was comforting and gave hope to these participants. For example, one woman shared "I pray every night and I always feel better after I do that. It gives me hope... I realize He knows what's best for me". Five participants stated that they specifically prayed for help dealing with their memory loss, "I pray at night when I go to bed and in the morning. I pray to be alert and to see another day". Four participants reported that they specifically prayed for their family caregivers"* (Beucher & Grando, 2009, p5).

Stuckey (2003) found that faith was linked to hope for people of different faiths including a Jewish carer of a person with dementia; *“I don’t know how I could cope without my faith . . . it really means so much to me. It gives me so much hope and strength”* (Stuckey, 2003, p344). Hope however was also important to carers who did not follow a religion in the study, with the researcher concluding; *“talking about religious and spiritual matters, even among the non-religious, can help bring hope and meaning to what might otherwise be abject sadness and despair”* (Stuckey, 2003, p350). Davis (1989) meanwhile who worked as a pastor, has described how his faith helped him when he developed dementia;

*“In the most helpless, hopeless, and extreme part of my life, Christ is here comforting and giving life meaning, even when all I have to look forward to is becoming a mindless vegetable. The assurance that another life is coming full of perfection and the reconciliation of all God’s creation gives hope”* (Davis, 1989, p68).

Dalby et al (2011) in their study of six older people living with mild to moderate dementia in Southern England, found that ‘keeping hopeful’ was a key theme seen in half of participants, while being understood gave people hope, as did faith in the efficacy of medications and feeling part of a divine plan. Other studies have shown belief in an afterlife to be sustaining and hope enhancing to people of different faiths (Snyder, 2003) because it could promise reunion with a loved one, but also through making people’s current situation more manageable knowing that stresses were temporary and that the reward of a utopian existence awaited them (Stuckey, 2003).

Fish (1991), in an account of her role as her mother’s carer describes how her diagnosis with dementia challenged her faith; *“why doesn’t God do something about Alzheimer’s Disease? Why did he allow it to happen in the first place? I thought God was good”* (Fish, 1991, p16). McCurdy (1998) meanwhile has written about the spiritual needs of carers, which he feels need full acknowledgment in order for person-centred care to be fully realised:

*“If the care assistant indeed feels helpless against the onslaught of dementia and holds little hope for the future of those in their care – perhaps believing that their only real “hope” is for a relatively peaceful, comfortable death – I would hold that this belief and its accompanying feelings can be seen as a spiritual problem”* (McCurdy, 1998, p83).

Some studies therefore demonstrate that spirituality and religion can enhance hope in some people with dementia and their families, but that dementia may lead to others questioning their faith. It is not clear what role hope plays in the strength of religious belief, or whether faith might develop in those who previously did not consider themselves spiritual or religious. This study

sheds further light on the relationship between hope, religion and spirituality in younger people with dementia.

## 2.11 Summary of what is already known

### 2.11.1 The importance of hope to people with dementia

The concept of hope has received surprisingly little attention in the dementia literature. Studies using quantitative and qualitative methodologies have come to different conclusions about whether hope is present in people with dementia and what it looks like. A small number of qualitative studies have commented on whether hope is important to people with dementia (see table 4 below), Aminzadeh et al (2007) for example describe hope as being critically important for people with dementia in transcending the losses and difficulties in their journey, although none except Radbourne (2008) have purposefully set out to investigate hope, and instead sought to understand the broader lived experience of dementia. Hope was found to be important and sustaining for people, and helped them to live in the present as well as coping with the future.

The importance of hope to people with dementia		
Findings	Researchers	Study type
Important to PWD	Clare & Shakespear, 2004; Aminzadeh et al, 2007; Radbourne, 2008; Beucher & Grando, 2009; Dalby et al, 2011; Pison-Young et al, 2012; O'Sullivan et al, 2014	Exploratory qualitative study with interviews; in-depth interviews & focus groups; qualitative interviews; ethnographic; exploratory qualitative study; qualitative interviews; action research using interviews & critical hermeneutics
Helps PWD to live in the present	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
Helps PWD to face the future	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
Hope as sustaining	Clare et al, 2008a; MacRae, 2008	Exploratory qualitative study with interviews; phenomenology/symbolic interactionism

Table 4 The importance of hope to people with dementia; summary of research to date (as of Sept 2016)

### 2.11.2 What people with dementia hope for

Several studies have offered insights into what people with dementia hope for. Many people had hopes connected to the present; for continuing to live and for and for maintaining abilities as long as possible (see Table 5). Other people hoped for ‘deliverance,’ through for example a miraculous cure (Lindstrom et al, 2006; Phinney, 2008; Radbourne, 2008) for having been misdiagnosed (Clare, 2002; Weezak & Stewart, 2002; Matchar & Gwyther, 2014). Hopes were not always for positive events however, people in some studies hoped for death before their illness progressed (De Witt et al, 2010) and Aminzadeh et al (2007) found that hopelessness and despair, as well as denial and crisis were common, with one participant saying *“in some situations, you’re better off dead”* (p285). In other studies several people with dementia spoke of helping others and how this brought them hope (McGowin, 1993; Davis, 1989; Henderson, 1998).

What do people with dementia hope for?			
Deliverance	Findings	Studies	Study type
	A cure/miracle	Lindstrom et al, 2006; Radbourne, 2008	Qualitative methods with exploratory focus groups; qualitative interviews
	Being helped by healthcare system	Robinson, 1998	Qualitative longitudinal study with interviews
	An afterlife	Snyder, 2003; Dalby et al, 2011; Stuckey, 2003	Qualitative investigation; phenomenological; grounded theory
	That God will hear them	Powers & Watson, 2011	Mixed methods
	Not really having dementia / misdiagnosis	Clare, 2002; Weezak & Stewart, 2002	Phenomenology; grounded theory
	For death before illness progresses	De Witt & Ploeg, 2006; De Witt et al, 2010;	Phenomenology
Helping others	That PWD will be treated with more respect & dignity	Clare et al, 2008b	Exploratory qualitative study with interviews
	That their writing will help others	McGowin, 1993; Davis, 1989; Henderson, 1998; Basting, 2003	Narrative
	To be able to offer hope to others	MacRae, 2009	Phenomenology/symbolic interactionism
Maintaining abilities including insight	That will know own limitations/when to stop	Genoe & Dupuis, 2012	Hermeneutic phenomenology
	That memory drugs will help	Stuckey, 2003; Clare, 2002; Lindstrom et al, 2006	Grounded theory; phenomenology; Qualitative methods with exploratory focus groups

			theory; qualitative interviews
	Not forgetting the important things	Clare & Shakespear (2004)	Exploratory qualitative study with interviews
	New drugs to protect against pathology	Genoe & Dupuis, 2012	Hermeneutic phenomenology
Continuing to live & enjoying life	To live more / longer	MacQuarrie, 2005; Phinney et al, 2007	Longitudinal qualitative study with interviews; Exploratory qualitative research
	That life will be liveable	Clare & Shakespear (2004)	Exploratory qualitative study with interviews
	A life of joy and meaning	Grayboys, 2012	Narrative
	To remain busy/active	Phinney et al, 2007	Exploratory qualitative research
	That able to stay positive/joyful	Phinney et al, 2007	Exploratory qualitative research
	To continue with friendships	MacQuarrie, 2005; Radbourne, 2008	Longitudinal qualitative study with interviews; qualitative interviews
	To read more books	Sorensen et al, 2008	Grounded theory
	To remain at home	MacRae, 2008	Phenomenology/symbolic interactionism

Table 5 What people with dementia hope for; summary of research to date (as of Sept 2016)

### 2.11.3 The nature of hope

Despite the limited number of studies to date, it has still been possible to gain some insights into the nature of hope people with dementia experience (see Table 6 on the following page). Their hope may be less goal-directed than that of the general population (Chapman, 2011), with generalised, rather than particularised hopes being common (Radbourne, 2008; Wolverson et al, 2010).

Hope could be fluid, and there was a complex interplay between hope and despair (Clare, 2002; Radbourne, 2008; Genoe, 2009; Wolverson et al, 2010; Genoe & Dupuis, 2014). Hope was realistic much of the time (Radbourne, 2008; Wolverson et al, 2010) and part of an active process that the person initiated themselves (Radbourne, 2008; Wolverson et al, 2010). Hope could be found in the here and now and was not lost despite the person's future being curtailed by their illness. In fact hope often sprung from the adversity that dementia brought (Preston et al, 2007; Radbourne, 2008; Wolverson et al, 2010).

The nature of hope		
Findings	Studies	Study type
PWD have less goal directed hope than controls	Chapman, 2011	Quantitative
Balancing act between hope & challenge/despair	Clare, 2002; Radbourne, 2008; Genoe, 2009; Genoe & Dupuis, 2014; Wolverson et al, 2010	Phenomenology; qualitative interviews; hermeneutic phenomenology; hermeneutic phenomenology; qualitative interviews
Hope fluid over time	Radbourne, 2008; Genoe, 2009; Genoe & Dupuis, 2014; Wolverson et al, 2010	Qualitative interviews; hermeneutic phenomenology; hermeneutic phenomenology Qualitative interviews
In the present	Radbourne, 2008; Wolverson et al, 2010; Graboys, 2012	Qualitative interviews; qualitative interviews; narrative
A force/energy	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
A resource	MacRae, 2008	Phenomenology/symbolic interactionism
Realistic & not wishful thinking	Radbourne, 2008; Wolverson et al, 2010; Graboys, 2012	Qualitative interviews; qualitative interviews; narrative
Active not passive	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
Generalised hope	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
Located within the soul	Graboys, 2012	Narrative
Adversity; dementia can uncover strengths such as hope	Preston et al, 2007; Radbourne, 2008; Wolverson et al, 2010	Phenomenology; qualitative interviews; qualitative interviews
Passed on through families	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews

Table 6 The nature of hope; summary of research to date

#### 2.11.4 Where hope comes from

Hope comes from a large variety of sources and could be either internally or externally generated (see Table 7). It could come the person doing work 'for the greater good' (McGowin, 1993; Davis, 1989; Henderson) by using a range of coping strategies (Clare, 2002; Radbourne, 2008; Genoe & Dupuis, 2014) and by staying positive (Phinney, 2008; Genoe & Dupuis, 2014). Hope could also be influenced by others. Many people with dementia placed their hopes in science (Henderson,

1998; Clare & Shakespear, 2004; Beard & Fox, 2008) while others placed it God (Snyder, 1999; Stuckey, 2003; Beucher & Grando, 2009, MacKinlay, 2012; O'Sullivan et al, 2014). Hope could also come from spending time with others (Genoe & Dupuis, 2014) including family (Snyder, 2001; Cutcliffe & Grant, 2001; Radbourne, 2008) and peers (Beard & Fox, 2008a; Clare et al, 2008b, Radbourne, 2008). Healthcare professionals could enhance hope by breaking the dementia diagnosis well (Aminzadeh et al, 2007), seeing people in memory clinic (Radbourne, 2008) and through the use of humanistic practice (Cutcliffe & Grant, 2001).

Where hope comes from			
Locus	Theme	What/who	Studies
External	Science	Research studies	Henderson, 1998; Clare & Shakespear, 2004; Beard & Fox, 2008
		Acetylcholinesterase inhibiting medication	Clare, 2002; Lindstrom et al, 2006; MacRae, 2008; Dalby et al, 2011
		Medical progress	Clare & Shakespear, 2004
	Religion/spirituality	Prayer & reading the Bible	Beucher & Grando, 2009; Mackinlay & Trevitt, 2012
		From living life according to Christian values	MacKinlay, 2012
		Tapping into faith, spirituality & life meaning	Stuckey, 2003; Snyder, 1999; MacKinlay, 2012
		Having faith in the future	O'Sullivan et al, 2014
	Family	Social contact with family	Snyder, 2001; Snyder, 2003; Radbourne, 2008; Genoe, 2009; Genoe & Dupuis, 2014;
	Professionals	Breaking the diagnosis well	Aminzadeh et al, 2007
		Attending memory clinic	Radbourne, 2008
		Nurses via humanistic practice	Cutcliffe & Grant, 2001
	Peers	Meeting peers at support groups	Beard & Fox, 2008
		DASNI membership/collective strength	Clare et al, 2008b
		Comparing situation with peers	Radbourne, 2008
		Information from other PWD	Pipon-Young et al, 2012
	General	Trust in reliableness/ responsiveness of envt/others	Robinson et al, 1998
		Spending time with others	Genoe, 2009; Genoe & Dupuis, 2014
		Being understood	Dalby et al, 2011
		Reminiscence with others	Radbourne, 2008



Internal	Working for the greater good	Writing to help others	McGowin, 1993; Davis, 1989; Henderson, 1998; Basting, 2003
		Taking part in research	Henderson, 1998; Basting, 2003
	Practical coping	Developing a system or set of strategies	Clare, 2002; Genoe, 2009; Genoe & Dupuis, 2014
		Planning ahead	Genoe, 2009; Genoe & Dupuis, 2014;
		Taking one day at a time	Radbourne, 2008
		Adapting to changing abilities	Genoe, 2009; Genoe & Dupuis, 2014
		Keeping busy	Phinney, 2007; Phinney, 2008; Radbourne, 2008; Genoe, 2009
		Leisure/activity	Genoe, 2009; Genoe & Dupuis, 2014; Radbourne, 2008
	Personal positivity	Maintaining an optimistic outlook	Genoe & Dupuis, 2014
		Humour	Snyder, 2001; Clare, 2002; Werezak & Stewart, 2002; McFadden, 2004; Preston et al, 2007; Genoe, 2009; Genoe & Dupuis, 2014
		Experiencing simple joys in life	Phinney, 2008
		Dealing with emotions	Genoe, 2009; Genoe & Dupuis, 2014
		Focusing on positive aspects	Genoe, 2009; Genoe & Dupuis, 2014

Table 7      What creates hope in people with dementia; summary of research to date (as of Sept 2016)

### 2.11.5 Barriers to hope

Barriers to hope identified in the literature (see table 8 on following page) include old age (Radbourne, 2008; Wolverson et al, 2010) and being excluded from drug trials (Beard & Fox, 2008). Progression of dementia and the symptoms this brought could weaken hope (Norman et al, 2004) but surprisingly stigma did not (Chapman, 2011) although the negative attitude of one person's spouse could (Clare & Shakespear, 2004). Loss of faith was another barrier to hope identified by O'Sullivan (2014) meanwhile.

Barriers to hope		
Findings	Studies	
Living with dementia	Nygård & Borell, 1998	Phenomenology
Stigma not a hindrance	Chapman, 2011	Quantitative
Old age	Radbourne, 2008; Wolverson et al, 2010	Qualitative interviews
Not having access to drug trials	Beard & Fox, 2008	Qualitative ethnographic
Negative attitude of spouse	Clare & Shakespear, 2004	Exploratory qualitative study with interviews
Loss of faith	O'Sullivan, 2014	Critical hermeneutics
Progression of illness	Norman et al, 2004	Qualitative interviews
'Existential threat'; threat to identity	Robinson et al, 1998	Qualitative longitudinal study with interviews

Table 8 Barriers to hope; summary of research to date (as of Sept 2016)

### 2.11.6 Conclusions

In conclusion, there is evidence from a large number of qualitative studies that hope is important to people with dementia, but very few researchers have set out specifically to investigate hope, and there is still much to be learned. In particular, there is a need to further understand barriers, and how professionals should best work with people's hope. This research asks directly about hope and adopts a mental health Recovery perspective, as to date this has been little explored empirically with people with dementia. It also makes particular reference to disability perspectives in order to understand the broader context of hope and how societal messages about dementia may impact upon the hope of people with the illness

## Chapter 3: Methodology and Methods

### 3.1 Aims and objectives and research question

This study addressed the following research question: *How do younger people living at home perceive hope, and how might their perceptions inform and improve community nursing practice?*

The aim of the research was to examine the phenomenon of hope from the perspective of younger people (those under 65) with dementia, in order to generate new understanding, and enable community based healthcare professionals to support people's recovery and well-being. This was an interest of mine because as at the time I was employed as a nurse consultant in a team supporting younger people with dementia. The research also sought to understand meanings and barriers to hope as people with dementia report them themselves and what might enhance hope. The objectives of the research were as follows:

1. To establish the significance perceptions of hope to younger people with dementia
2. To understand where people feel their hope comes from and what allows it to flourish
3. To identify the barriers to people with dementia feeling hopeful

It was recognised that some people may not feel hopeful, or may even hope for death. For the purposes of this study the person's experiences were validated (acknowledged that this is how they feel) without necessarily condoning their point of view, or conversely dismissing their experience and pressurising the person into appearing hopeful. This approach might also be useful in clinical practice when working with people with dementia alongside 'holding hope' as described in the mental health recovery approach.

### 3.2 Methodology

This study is underpinned by social constructionist ideas and subjectivist ontological assumptions that no objective reality exists, but that people create their own subjective meanings as they interact with the world around them. Concepts such as 'hope' and 'dementia' are therefore highly individual in their meaning and are heavily value laden. An attempt has been made to access these individual meanings with qualitative, visual methods in order to better understand the

context of, and complexity of each person's ideas. Photo diaries were used to create a visual record of what people feel makes them hopeful, facilitate conversation about their meaning and make visible the "*whole person*" with dementia (Bartlett, 2012). This draws heavily on work from social sciences, and health sciences including some of the Humanist concepts from positive psychology; that humans have their own unique way of viewing the world, and have a tendency towards growth (or 'Recovery'), the key to unlocking potential therefore being to understand what individuals believe. An epistemological assumption was that subjective knowledge (the person's own views and experiences) is the most important form of knowledge. Qualitative, in-depth interviews were used with inductive, rather than deductive reasoning utilised to carry out readings of the data in order to uncover the person's story and any underlying power relationships.

Brown and Gilligan's (1992) Voice-Centred Relational method, also utilised by Paliadelis and Cruickshank (2008) in a healthcare setting, was used to interpret the data. The methodology requires the researcher to carry out four readings of the data; firstly, the story and who is speaking, secondly 'in what body' (how people speak about and appear to feel about themselves), third telling what story about relationships, and lastly in which societal and cultural frameworks (Brown and Gilligan, 1992). This framework was chosen due to its emphasis on hearing the voice of disempowered people and entering their reality. This fits well with previous work which has emphasised the importance of hearing the voice of people with dementia (Goldsmith, 1996) and also of the need to enter their world (Stokes, 2008). The approach is designed to uncover power relationships, a central part of both recovery and critical approaches already discussed, in particular the work of Bartlett and O'Connor (2007) who emphasised the importance of the broader socio-political context to dementia care including power imbalances.

### **3.3 Research Design**

This in-depth, interpretive study drew on narrative approaches. It used qualitative methodology through a modified diary-interview method, involving photo diaries.

### **3.3.1 Setting**

The study took place in the Midlands, England. It involved participants who live in their own homes because community settings are where most people with dementia live. It is also a more naturalistic setting where people may experience a greater sense of control over their lives compared with for example a hospital setting where there may be interference from outside forces impacting upon their sense of hope. The community setting has much in common with previous empirical work that has highlighted hope as being important to people with dementia.

### **3.3.2 Sample size**

Six people with dementia between the ages of 18 and 65 years were recruited to the study, which was the target sample. This was considered to be a number which was manageable both conceptually and practically, allowing for repeat interviews and for a sufficient depth and quality of rich data to be generated. The Voice-Centred Relational method is also complex and time consuming (Mauthner & Doucet, 1998) which is a factor in choosing this relatively small sample size.

### **3.3.3 Inclusion criteria**

To meet the inclusion criteria all participants needed to be able to give informed consent in line with the process consent method (Dewing, 2007), and demonstrate insight into their illness, which was ascertained by the researcher during an initial interview. The suitability of each person to take part was additionally determined by a dementia advisor working with the person prior to meeting with the researcher. Participants with any type of dementia, and at any stage of their illness were able to take part, providing dementia been formally diagnosed and they have the capacity to consent to taking part.

### **3.3.4 Exclusion criteria**

Participants over the age of 65 at time of diagnosis, those currently living in care homes, or who were staying in hospital were excluded from the study. Participants who were unavailable for interview within a reasonable timeframe (two months), those who were unable to speak fluent

English (people with severe language deficits were not able to take part) and people unavailable to be interviewed in the local area, for logistical reasons, could not be take part in the study.

It was originally envisaged that people with dementia who lacked mental capacity but gave their assent would also take part, but ethical approval was not granted, meaning that people who took part needed to have capacity and be able to give informed consent. Clients who were care co-ordinated by myself in my clinical work were also not able to take part in the study in order to prevent any conflict of interest being introduced, and any desire on behalf of participants to please the researcher.

People who had marked challenging behaviour or who were assessed as presenting a risk to the researcher (e.g. due to aggression) could not take part. People with co-morbid conditions which impact considerably on day to day life (e.g. depression or unstable diabetes) were also excluded as these conditions were thought to be likely to confound results and to make findings harder to interpret. It was anticipated that people with significant sight or hearing problems would not take part as these were likely to inhibit their full participation in interviews and in taking photographs. However a partially sighted woman did in fact take part as she made it clear that she would be able to take the photographs with help.

### **3.3.5 Participant selection and recruitment**

Purposive sampling methods were used to recruit six people to the study. The intention was to draw people from three sources; the caseload of a specialist NHS team for younger people with dementia (where I worked as a Nurse Consultant), the caseload of 'dementia care advisors', and from support groups and services in the surrounding area for younger people with dementia. Unfortunately recruitment via the dementia care advisor service was not possible as the service was discontinued. It also proved more difficult than expected to recruit participants through the younger people with dementia team, and in the event all participants were recruited through an organisation which facilitates support groups for younger people with dementia. Participants were recruited to the study in line with the recruitment process outlined in the flow diagram in appendix D. The teams and facilitators of support groups had been briefed on the study in various ways including face-to-face presentation, telephone conversation, informal discussion and a flyer (see appendix E) which clearly states the inclusion criteria. Team members were asked to consider people on their caseloads who might be suitable for the study, and to contact me if they feel that they know someone who might be appropriate. Suitability of people was then discussed with staff to ensure that they are likely to meet the inclusion criteria before they are contacted by phone or

e-mail or are given a flyer by the healthcare professional. The facilitators of local support groups were also contacted and given details of the study. It was then discussed with them whether they feel anyone who attends their group might be interested in the study and would meet the criteria before flyers were given to the facilitator to invite the person to take part.

People who responded indicating that they would like to take part in the study were sent an invitation letter (see appendix F). The letter outlined the purpose of the study, and explained clearly and in plain English what would be involved. It was made clear that participation is voluntary, and that they are under no obligation to take part. A stamped, self-addressed envelope was supplied with each letter (where applicable, many chose to reply via e-mail), and also a form enclosed for the person to return indicating whether they would like to take part, and giving their consent for me to obtain basic information about them (e.g. contact phone number, date of birth, diagnosis) if they had a care co-ordinator.

Care was taken to ensure that staff were kept up to date with recruitment numbers to prevent over recruitment. Potential participants were sought in small numbers while the process of obtaining consent took place. Each potential participant was sent a letter inviting them to take part in the study. People who had been sent letters were given three weeks to respond before a reminder letter was sent out. No further correspondence was entered into following this time if the person did not respond, and it was assumed that the person was not interested in taking part. Participants who returned the form indicating that they did not wish to take part were not contacted again. Efforts to recruit participants continued until six people had been successfully recruited who fully met the criteria for inclusion.

Once a form was received by the researcher indicating that the person would like to take part in the study, the person was contacted according to their preferences stated on the form in order to arrange an initial meeting. This meeting took place at a time and place suitable for both the person and the researcher, including evenings and weekends. This could for example be held at their normal place of residence, the home of a family member or on NHS property but would not include a public place where conversation could be overheard by others (thus breaching their confidentiality) or where background noise would inhibit effective audio recording. The option of meeting the person at their home was given in order to prevent the person incurring travel costs, and it was thought that this environment might also facilitate a greater understanding of the person and their life. Confirmation of the date, time and place of the meeting was sent to the person in a letter which was sent in the post.

At the initial meeting I introduced myself and gave details of the study. It was made clear that participation in the study was voluntary, and the person was not put under any pressure to take

part. During this meeting the person was asked some basic details about themselves and their health which were recorded on a pre-prepared pro forma. People who did not spontaneously mention their dementia were asked whether they had any problems with their memory. If the person said that they did, they were then asked if they minded the researcher asking more about this. If they agreed, they were asked to describe the sorts of problems they had been experiencing, and then asked whether they knew what was causing the problems with their memory. It was anticipated that through this gentle line of questioning it would become clear whether the person was aware of their dementia diagnosis. If a person showed signs that this was upsetting them, or they did not appear to realise that they had a dementia diagnosis, or they were unable or unwilling to fully answer the questions, the interview was planned to stop and the person would have been thanked for their time and told that unfortunately they were not be able to take part in the study. They would then have been given a leaflet which described routes to participating in other research through the work of the local Dementias and Neurodegenerative Diseases Research Network (DeNDRoN).

Participants who met all of the inclusion criteria were asked to sign a consent form confirming that they agreed to take part and understood what would be involved including consent to be audio recorded. Consent was assessed using the 'process consent method' (Dewing, 2007) which has been designed for research with people with dementia and which aims to maximise their involvement and inclusion. It takes account of the fact that capacity is situational and fluid and requires consent to be continually assessed. The process consent method has five stages which involves the preparation stage (clarifying the permission of others close to the person), establishing the basis for consent (understanding their usual presentation and what ill-being and wellbeing look like for them), gaining initial consent (providing information in a way that they understand, enabling the person to handle props - such as a camera where necessary, and evidencing this consent or assent through recording of body language facial expression), ongoing consent monitoring (revisiting consent on every meeting and checking that their feelings have not changed) and feedback and support (seeking permission on how to feedback to others and how to keep in touch with others close to the person, should for example it be a bad day for an interview).

Signed copies of the forms and evidence of the process consent method once carried out were retained by myself and kept in a locked filing cabinet on NHS premises in accordance with national and local data protection requirements.



### 3.3.6 Procedure

Once consent had been obtained at the initial meeting a 'cooling off period' of approximately one week was provided where participants had the chance to change their mind. The pre-diary meeting then took place at an agreed time and place once participants had had time to read fully and digest the information provided. This could again be at the person's home if this is where they felt the most comfortable. It was checked at this pre-diary meeting that participants continued to give their consent to take part in the study, and as before the process consent method was utilised where applicable (Dewing, 2007). Participants were invited to ask any questions they had about the study and these were answered honestly and openly. If participants still wished to take part they were given a disposable camera (chosen for ease of use), and provided with training on how to take pictures. They could also use their own camera if they preferred. Instructions given involved verbal and written information and a demonstration on the use of the camera, allowing the person to handle it, and checking that they were comfortable using it and able to take photographs. If they were not able to use a camera, this did not exclude them from the rest of the study. They were asked to take pictures over the coming month of things that made them feel hopeful. A written reminder of their task was provided and left with participants (see appendix G) in order to reduce the cognitive burden on participants to remember the instructions. The pictures once taken and developed by the researcher formed a photo diary which the person retained after the interviews were complete. Participants were advised both verbally and in writing not to take pictures of people without their permission.

A stamped addressed envelope was provided in order to post the camera back to me for developing when the person had finished taking pictures. Participants were advised that ideally, they should complete this task within a month, and that they did not need to use up all of the pictures if they did not want to. They were given my number and e-mail address to contact on a card in case they felt that they needed any further assistance or support. A telephone call was made to the person after two weeks to see how they are getting on and to ask if they need any support in completing the task if no contact had been made (unless a prior agreement was in place, several participants for example went on holiday immediately after being recruited). Further phone calls and face to face visits were made available if the person felt that they needed this to complete the task, or had any questions or queries about the nature of the research. If a camera was not received back from the person within four weeks, the person was contacted to enquire how they were getting on and to see whether they needed any support. The camera was professionally developed. If the person had decided that they did not want to take part in this part of the task, then this would not have prohibited them continuing to the next stage.

Photo diaries have been utilised previously by Turner (2004) amongst many, who used photographs to capture hope through the eyes of ten Australian young people who were in mental health crisis. The technique appeared to be effective at eliciting themes relating to hope, although no comment was made by the authors as to the acceptability of the technique to participants. Aldridge (2007) has similarly used the technique with a vulnerable group, people with learning disabilities. It was found to be useful as it did not rely upon a verbal response from participants, allowed direct entry into the person's point of view and facilitated inclusion in a group otherwise at risk of not having their voice heard. As 'photovoice', the method has been described by Newman (2010) as having the ability to enable participants to function as partners in the research process. It has been used by Carlson et al (2006) as part of community based participatory approach aimed at generating social change within a lower income African American urban community. The photographs were said to have put the agency for change into the hands of people within a historically marginalised and oppressed community. Levin et al (2007) similarly found photography to be empowering, and a means of enabling self-expression and communication in people with aphasia following a stroke.

Although not used as a primary source of data in this study with people with dementia (it was used to facilitate discussion) it was hoped that the people with dementia might similarly find it an empowering experience, and that it might enable insight into their world in a way that might otherwise not be possible due to the nature of their cognitive impairment. Bartlett (2012, p1723) has described the use of photo diaries in study of 16 people with dementia and how these enabled a participatory approach, giving people the opportunity to take control of the content and pace of data collection, and facilitating an equal relationship between participants and the researcher by making visible the 'whole person.' Interestingly one participant felt that hope was an underlying theme of his diary (Bartlett, 2012). It has also been used by Genoe (2009) in a phenomenological study examining the meaning of leisure to Canadians with dementia, which also discovered that 'hope' as well as 'challenge' were common themes. Moore (2012) meanwhile has specifically used the technique to explore how 12 older adults (without dementia) experienced hope in their day to day lives by asking them to take photographs of things that represented hope for them. Photographs were used as prompts for subsequent interviews, as they have been in this study. The method appeared to have been successful, and a surprise finding was that the act of looking for hope actually enhanced the level of hope that participants reported.

On the day of the post-diary interview, consent was again sought from participants using the process consent method (where applicable) before proceeding. Interviews were audio recorded using a digital voice recorder, which was checked at the beginning of each interview to ensure

that it was working and able to pick up the voice of the researcher and participant clearly. Participants were encouraged to relax and to act as if the recorder was not there. Interviews took the form of a conversation with prompts available which are described in more detail in the data collection section below. The developed photographs were described by the researcher for the purpose of the audio recording, and discussed with the person who was asked about hope and whether their level of hope has changed at all since the last meeting to see whether similar results were produced to Moore's (2012), that the methodology actually generated hopeful feelings. Reasons for any difference were enquired about in an attempt to understand this further. At the end of this post-diary meeting the person was thanked for their time and asked whether they would like to be sent a summary of the meeting (this was sent to them through the post if they wished to have a copy).

### **3.3.7 Data collection**

During the second half of the initial meeting (once eligibility had been established and consent given) a general discussion took place about the person's life and what is important to them. Notes were taken by the researcher on a pre-prepared pro forma. topics of conversation included where the person was born, whether they had lived in the area long, if they had friends and family locally, had any pets, were religious, lived with anyone else, what their hobbies were and what they had done (or currently still did) for a living. This discussion is designed to develop an understanding of the person, and help to gain rapport. This was framed as a 'getting to know you' conversation, and partners of participants were welcomed to join in, and in some cases contributed some of the information.

During the post-diary interview a conversation about hope took place, which was planned to last no longer than an hour. Efforts were made to build rapport with participants and to help them to feel comfortable. The conversation was recorded using a digital audio recorder. Some question prompts were brought to the interview to ensure that key areas are all explored, but the conversation structure was free-flowing and was led where possible by the person and what they wanted to discuss. Question prompts included:

- Would you say that you are a hopeful person?
- What makes you hopeful?
- Is hope important to you?

## Chapter 3

- What do you hope for in life at the moment?
- Has this changed at all since the dementia diagnosis? How has it changed?
- Can other people change your level of hope? How?
- Is your level of hope always the same or does it change? Do you ever feel despairing?
- Does anything reduce your hope?
- Is there anything else you'd like to say about hope?

Attempts were made to make the questions simple, understandable and free from jargon to enable participation. Care was also taken to ensure that many questions were open, not closed, in order to elicit more in-depth information.

The developed photographs formed a key part of discussion but did not represent data in themselves and are not reproduced or stored by the researcher. They were instead a tool to assist with eliciting the views of people on hope. The person was asked about whether their level of hope had changed since the last meeting and the reasons for any difference.

### **3.3.8 Data analysis**

The interviews were transcribed and a typed copy as well as an audio copy was kept by me. The 'Voice-Centred Relational Method,' a Feminist approach based on the work of Gilligan (1982), was used to read and make sense of the data. The method had previously been used to understand the experience of motherhood and post-natal depression (Mauthner & Doucet, 1998), the experience of being an older nurse (Letvak, 2003), of being in workplace transition (Balan, 2005) being a trainee (Fairtlough, 2007) and of being a nursing unit manager (Paliadelis & Cruickshank, 2008). It was chosen primarily due to the advantages it offers over traditional coding based methods as discussed by Mauthner and Doucet (1998) who have both used the Voice-Centred Relational method in their own doctoral research. They highlight that strengths include its ability to track voices, to seek new knowledge and recognises differences, rather than seeking to elicit themes and fit the person into pre-existing categories (Mauthner & Doucet, 1998). The approach allows the person's voice to be more authentically heard and, as Mauthner and Doucet (1998) have highlighted, without this there is a risk that studies will otherwise only confirm what is already known (or what the researcher thinks they know). Reflexivity (the recognition of how

one's own social identity and background may impact on the research process; Gerrish & Lacey, 2010) is seen as important in qualitative research because it helps to avoid researcher bias (Etherington, 2004). The Voice-Centred Relational Method can assist with reflexivity because it requires the researcher to document their own responses to the person, and to examine their own assumptions and beliefs as part of the first reading. In this study reflections were written directly onto transcripts as part of the data analysis process. These were also discussed with project supervisors during analysis of a sample of the transcripts, and I undertook the photography task myself to better understand how my understanding of hope might have compared with participant's.

A key aim of Feminist research is to empower women and other groups who occupy marginalised or oppressed positions in society (Campbell & Wasco, 2000). The ability of the method to uncover power dynamics (Paliadelis & Cruickshank, 2008) is crucially important to the study of people with dementia who experience considerable negative attitudes in the social discourse (O'Sullivan et al, 2014) and unequal power relationships, particularly in research (Nolan et al, 2002). Power relationships are also a central concern of both Recovery and critical approaches which, as already discussed, may have particular relevance to people with dementia. The method also allows exploration of the broader socio-political context of dementia which is important to understanding the person's response to having dementia. This has traditionally been neglected in favour of biomedical and psychological models (Downs, 2000; Bartlett and O'Connor, 2007) which focus on pathology and the 'tragedy' of dementia (Downs, 2000), leaving no room for hope. The methodology requires the researcher to carry out four readings of the data; firstly, the story and who is speaking, secondly in what body (how people speak about and appear to feel about themselves), thirdly 'telling what story about relationships', and lastly in which societal and cultural frameworks (Brown and Gilligan, 1992). These readings enable an in-depth insight into the person's world. This fits well with previous work which has emphasised the importance of hearing the voice of people with dementia (Goldsmith, 1996) and also of the need to enter their world (Stokes, 2008). An example of this method in use can be seen in appendix I which also includes examples of data being arranged into themes.

### **3.3.9 Ethics consent and approval**

Approval was granted by the University of Southampton's Research Governance Office, the NHS Research ethics committee and my employer at the time; Northamptonshire Healthcare NHS Foundation Trust (NHFT) on the basis that the research was likely to involve service users.

People with dementia have often been excluded from research due to their perceived vulnerability (Bond & Corner, 2001). There is evidence that people with dementia may derive benefit from taking part in research however. In addition to having their voice heard, people with dementia may find diaries to be particularly therapeutic (Bartlett, 2012) and may have a desire to help others with the illness (Valimaki et al, 2007). Traditional methods of seeking informed consent have often used cognitive based assessments (such as MMSE) to screen out those with more marked cognitive impairment (Dewing, 2002), despite evidence that such tests may cause distress (Hellstrom et al, 2007) and may be of little benefit in deciding whether or not a person is capable of giving their views (Hellstrom et al, 2007). Cognitive based assessments will not be used for these reasons. There is also concern about proxy consent (Dewing, 2007) which excludes the person from the decision-making process, and this form of consent will therefore not be used in this study.

This research draws upon the ethical framework described by the Nuffield Council on Bioethics (2009), in particular the emphasis on a good quality of life being attainable for people with dementia, of the need to promote their interests, to recognise their citizenship, and to recognise their personhood, identity and value. It also takes a participatory approach (Aldridge, 2007) in which attention is paid to balancing power between the researcher and the participants. As Bartlett (2012) has pointed out, this is especially important when undertaking research with people with dementia, due to historic imbalances of power in the research process.

In line with best practice, throughout the research process there was no deception involved. Participants were fully briefed about the purpose of the study in an open and honest way, and given information about the results of the study at a later date if they so wished.

Risks identified were inconvenience to participants, the possibility of distress, and threats to the personal safety of the researcher, although steps were taken to minimise these risks as much as possible. It was hoped that the use of a photo diary would reduce the burden on participants to remember, and therefore minimise distress by allowing them to record their thoughts in the form of photographs in their own time at their own pace (Bartlett, 2012). In order to further reduce the likelihood of distress to participants the advice given by McKillop and Wilkinson (2004) was followed, which was based on feedback from a person with dementia with experience in being

interviewed. Interviews were not overly long, people were regularly offered breaks, or the chance to continue the interview later if they appeared tired or the meeting has reached an hour and a half. A small and unobtrusive notebook was used rather than paper notes or forms to avoid formality. The risk of distress being caused was also reduced by the researcher having already met each person previously and established rapport, by participation being voluntary, the relaxed style in which interviews were conducted, and the interviews being held at a place of the person's choice where presumably they would feel most comfortable. Participants were welcome to leave the interview at any point and this was made clear to them at the outset, and again if they appeared to be becoming upset (although this fortunately was never an issue).

To minimise threat to the personal safety of the interviewer while carrying out interviews the whereabouts of the researcher was recorded in a diary and a nominated person was told when to expect a call from the researcher to say that the interview has finished and the researcher had left. In line with local lone working policy if any problems arose the researcher would have rung the nominated person and asked for the 'purple folder', thus activating the local NHS protocol for assisting a person in trouble. The researcher ensured that when meeting people in their own homes potential escape routes were identified, that had the situation appeared to become risky then the interview would have been terminated, and a mobile phone was carried at all times.

Findings have been disseminated to participants, staff working within NHFT and to other staff who have assisted with the recruitment process (such as facilitators of local groups) via a summary sheet which outlines key messages but keeps data relating to individual participants anonymised. A typed summary record was created for each participant after the final interview and sent to them by post. This enabled the person to see tangible output from the interviews, in a way that is understandable to them and would not overwhelm them with large amounts of data. The summary record attempted to capture the essence of what was said in lay language, and tentatively drew conclusions (e.g. *"you told me this..."*, *"it sounded like you thought this..."*) and contained any relevant quotes (e.g. *"I really liked it when you said this...can I put it in my write up?"*). The person was thanked for their input again, and asked to contact the interviewer if they saw anything that appeared incorrect or any information that they would rather was not used in the write up. Findings will be disseminated through the submission of a doctoral thesis, and to other researchers via the University of Southampton biannual research conference. It is anticipated that a write up of the study will also be submitted to a journal for consideration of publication.

### **3.3.10 Confidentiality and storage**

The confidentiality of participants was maintained by ensuring that consent forms, and a copy of the audio recordings were stored on a memory stick, and any correspondence entered into was kept in a locked filing cabinet. Participants are not identifiable from the transcripts, each was assigned a code and a pseudonym, and if participants mentioned their name or the name of others during the audio recording, this was redacted. The transcripts were seen only by myself and my project supervisors. A short summary of the transcripts and what was discussed was created and sent to participants who indicated a wish to receive this. The consent forms included the person giving permission to use extracts from the interviews, but as already described this was also checked again with the person after the interview and it was asked whether there was anything that they have said that they would not wish to be published. The codes assigned to participants were kept in a locked filing cabinet. Interviews did not take place in public areas where conversation could be overheard. All data including the transcripts was stored and retained in line with the University of Southampton's protocols for the secure storage and retention of these documents, which is that the project supervisor will take responsibility for archiving and destroying the dataset in 10 years' time

### **3.3.11 Profiles of participants**

A summary of participant demographics can be seen on the following page, followed by more detailed profiles.



Pseudonym	Richard	Ann	Matthew	Robert	Rachel	James
Age (at recruitment)	64	60	54	57	54	60
Gender	Male	Female	Male	Male	Female	Male
Dementia type	Alzheimer's Disease (AD)	Posterior Cortical Atrophy (rare form of AD)	AD	AD	Vascular Dementia	AD
Diagnosis date	2014	2011	2015	2014	2012	2013
Interview date	26/09/15	19/09/15	19/12/15	14/11/15	27/01/16	23/04/16
Any others present during interview	Wife	Husband	Wife	Wife	N/A	Wife
Relationship status	Married	Married	Married	Married	Single	Married
Children	Yes	Yes	Yes	No	Yes	Yes
Others living in house	Wife	Husband	Wife and children	Wife	N/A	Wife
Religion	C of E	Not religious	Not religious	Not religious	Mixture of beliefs	Not religious
Employment status	Retired	Retired	On sick leave	Retired on medical grounds	Unemployed	Retired

Table 9 Summary of participant's demographics

*Richard*

Richard was 64 years old when he was recruited to the study. He lives in the countryside with his wife and their dogs. He is highly educated and has worked in a number of industries. He is now retired from work.

He was diagnosed with Alzheimer's Disease a year prior to the interview taking place. He believed that his symptoms began perhaps four years prior to his diagnosis. His father also had dementia.

### Chapter 3

He has problems with his short-term memory, but the thought of losing his driving licence one day scares him the most. He recently took a driving test which he passed. He drives a lot, partly through his work as a volunteer driver and said that driving is strongly tied in with his wellbeing.

Richard has many hobbies and is an active person in his local community, regularly attending a number of clubs. He also enjoys music, watching cricket, going on walking holidays, and has a strong interest in model railways. At the time that he was recruited to the study Richard was about to go on holiday which coincided with the photography task. He described himself as an extrovert and someone who *“likes to talk”*.

#### *Ann*

Ann was 60 years old when she was recruited to the study. She has lived in her current home for over ten years. She used to work as a manager and always enjoyed her work. After her diagnosis of a rare form of dementia; posterior cortical atrophy 4 years prior to the interview, she left her job and has found it difficult to do any other kind of paid work since. To date her illness has primarily affected her processing of visual information and she describes herself as partially sighted. She sees images as blurry and struggles to focus. Colours can sometimes be distorted also, which is a common characteristic of this form of Alzheimer's Disease. She can no longer drive which she finds extremely frustrating, and is accompanied whenever she leaves the house. When her sight problems meant that she was struggling to keep up with her duties she stopped work altogether. She and her husband then decided to get a dog to keep her company, and she regards this as one of the best decisions they ever made. Another decision she is grateful for is their decision to carry out work on their house (recently completed) which involved creating a large extension for her to sit in during the day, and an area off this to be used as a bedroom when she needs this later in her illness. The new lounge area is light, sunny, and overlooks one of her great loves, her garden. This was the location of the interview. She has a number of hobbies and particularly enjoys gardening, going on holidays, and attending the Edinburgh Fringe festival. She said that prior to her illness she used to 'live in the garden'. She described herself as *“never academic”* but someone who had always been quite busy, sociable, determined and positive in her attitude.

#### *Matthew*

Matthew was 54 when he was recruited to the study and was the youngest person to take part. He lives in a village with his wife and their two teenage children. He was an only child and grew up

in the west of England. He had a career in IT before becoming a teacher, and spoke fondly of his pupils and how much it meant to him to see them succeed. He was unable to work and was on sick leave at the time of the interview. He said he was open about his diagnosis and regularly came across people from the school who didn't know, and it could be difficult and emotional breaking this to them. He enjoys socialising with friends, and has a number of hobbies including riding his bike, and walking with his family in the countryside. They have a dog who he also enjoys going on walks with, and like Ann this is his first dog. He described himself as someone who is outgoing, jolly, positive, and is the joker in the household. He said that following his diagnosis and stopping work this has become harder. He said that he is determined not to feel sorry for himself and is someone who now lives a lot in the moment. He and his wife commented that he has become a 'house husband' over the last few months and has taken on new roles and responsibilities in the household which he has grown to enjoy. They have lived in their current house for several years and feel very settled in their local area.

### *Robert*

Robert was 57 and was born and raised in Wales. Like Matthew he was an only child. He studied agriculture and horticulture at college, later obtaining a national diploma in horticulture. His mother died when he was young and his father passed away a few years ago. He has an aunt who still lives in Wales who was a mother figure to him after his mother died, and he still sees her from time to time. He has no other living family except his wife. They are close, and live together in a house in a modern housing estate in a village. They have a cat who he is very fond of and who he enjoys spending time with during the day. Robert describes himself as not having any particular religious beliefs, who has a good sense of humour, enjoys watching golf, but most of all is devoted to gardening. He has worked in horticulture all of his life and has worked in a number of prestigious places, both locally and further afield. He proudly showed me pictures of gardens he has created and maintained over the years and had lots of interesting stories to tell. As his wife noted he is a friendly but slightly shy person by nature and surprisingly therefore he has engaged a number of passing celebrities in conversation while at work. He retired recently on the grounds of ill health. He clearly missed working, but agreed with his wife when she said that stopping work had in many ways taken the pressure off him. He spends a lot of time working on his own garden now, and has been focusing on various projects to make the garden smarter, and more manageable for his wife in future years. He has always worked hard and is as dedicated to his own garden as all the others he has tended over the years.

### *Rachel*

Born in the south of England and of Afro-Caribbean decent, Rachel was 57 at the time of being recruited to the study and lived alone, her daughter having recently moved out. Her parents worked in the UK all their lives and moved back to the Caribbean a year ago (she chose not to go too). Her father was in the army when she was a child and they moved around a lot as a family. She said that she was brought up to be very cosmopolitan therefore. Her parents ran nursing homes together for many years and so she spent time herself around people with dementia and other health needs. Her siblings also live in other countries and she is therefore not able to see them as often as she would like.

Rachel worked as a professional photographer, taking pictures for calendars, magazines, studio pictures for fashion shoots, and food. She specialised in portraits, enjoying the contact with people. She lived abroad for many years and for a time she owned her own businesses selling gifts and specialising in interior designer. She separated from her husband while abroad several years ago. When she began developing subcortical vascular dementia three years ago she had to stop work, and eventually returned to the UK. This was partly because she was dissatisfied with the medical care she was receiving (this included a period of hospitalisation for challenging behaviour, and a regime of medications). She no longer takes the medications or exhibits any behavioural disturbance. She said that her craft work (making mosaics) is like her job now.

She has lived three years in her current property and said that she feels geographically quite isolated, needing her car to get around. She is worried therefore what will happen when she has to stop driving. She is supported by a local charity who provide a support worker who works with her regularly. She keenly reads books written by other younger people with dementia. She does not go to church but describes herself as spiritual. She said she likes to 'mix' her faiths and her beliefs are mainly a mixture of Buddhism and Christianity. Her main hobby is making mosaics which she sells and gives the profits to the dementia charity that supports her. She also likes music, gardening, walking, photography and adult colouring books. She used to love cooking but is no longer able to do this as she finds it hard and tends to burn things. She used to enjoy going to the Notting Hill Carnival but now finds it too busy and overwhelming.

She described herself as optimistic and "*up for a challenge*", and she is always looking for strategies to get around things. She said that she believes in herself, and listens to her body, knowing when she is having a bad day with her dementia and takes steps to reduce risk (for example she will not drive). She said that she also has quite a scientific and analytical mind.

*James*

James was born in the Midlands and was 60 years old when recruited to the study. He was diagnosed with Alzheimer's Disease in 2013 at a nearby hospital. He takes a low dose of a cognitive enhancing medication, having experienced difficulties with side effects at higher doses. He was from a large family and is married, with children from his wife's previous marriage and two grand-children. He and his wife have lived in their current property, a detached house in the Midlands for 30 years. James is now retired from work and has worked in a variety of roles during his working life including purchasing and sales. He has a large number of hobbies including; snooker, supporting his local football club, table tennis (he is part of a local team), cricket, rambling, working on his allotment and going on foreign holidays. James described himself as a quiet, laid back person, in his words "*part comatose all the time*". He said of his personality "*I don't have one*", but he also described himself as competitive and someone very into sports. He is not religious and does not have any pets.

## Chapter 4: Results overview

### 4.1 Hopefulness; hope despite dementia

All participants used the word 'hope' spontaneously during their interviews; saying for example "I hope" and spoke in a hopeful way about the future, anticipating positive outcomes. This is explored further in chapter 6; 'what participants hoped for'. How hope is spoken of (in terms of its qualities) is discussed in chapter 7, while chapter 8 looks at the sources of hope, and chapter 9 what impedes participant's hope.

As will be discussed, hope was realistic and none of the participants appeared to yearn for something more in life than they had, and the hope that they expressed was not wish fulfilment. Ann expressed this as *"I have more good things in my life than bad things"* and Richard, on being asked what he hoped for replied; *"oh I think we've got most of what we want here."*

All participants said that hope was important to them, with the exception of Richard, who said *"not to the point that I worry about it"* suggesting that (consciously at least) it was not important to him. Ann meanwhile gave a very different answer; *"well if you don't have hope what do you have?...really...at the end of the day? Doesn't matter what your trouble is...you know if you don't have hope to get through it you might as well just kill yourself...do you know what I mean?"* demonstrating that she felt hope was essential to her, and in fact to everybody.

Hope was present in all participants, both in their photographs and in the interview transcripts. Having dementia could make Matthew feel less hopeful at times but most of the time he stayed positive; *"do you know that I'm happy most of the time actually"*. Using a voice-centred model it is possible to discern that Matthew felt surprised at the fact that he felt happy despite having dementia, and perhaps expected others to believe that this would not be possible. James expressed similar satisfaction with life; *"life's good at the moment"*. Living with dementia brought him a sense of perspective, and he felt that it did not hold him back; *"there are things now that I know that are minutiae that that you know just forget those...park those...um...and the dementia really doesn't impede me doing things"*.

Richard also remained determined to reach the goals he set himself despite his dementia; *"I hate giving in"* as did Ann who had the following advice for other people with dementia; *"Perhaps the only thing I'd ever say to somebody with something like this is...never let hope go...d'you know what I mean? Keep hopeful...and erm...you know that you can't get better but you can still....have"*

*a jolly good time!*". In this way she showed resistance to societal messages that living well with dementia was not possible.

## 4.2 What participants hoped for

What participants hoped for was diverse and largely governed by their personalities and interests, however five over-arching themes could be determined. These were; good health, enjoyable events, contact with others, success in their endeavours, and hope for a better world. These and the sub-themes for each can be seen in figure 8 below, and in greater detail in appendix H. Together they symbolised participant's belief in a future, for themselves and for others.

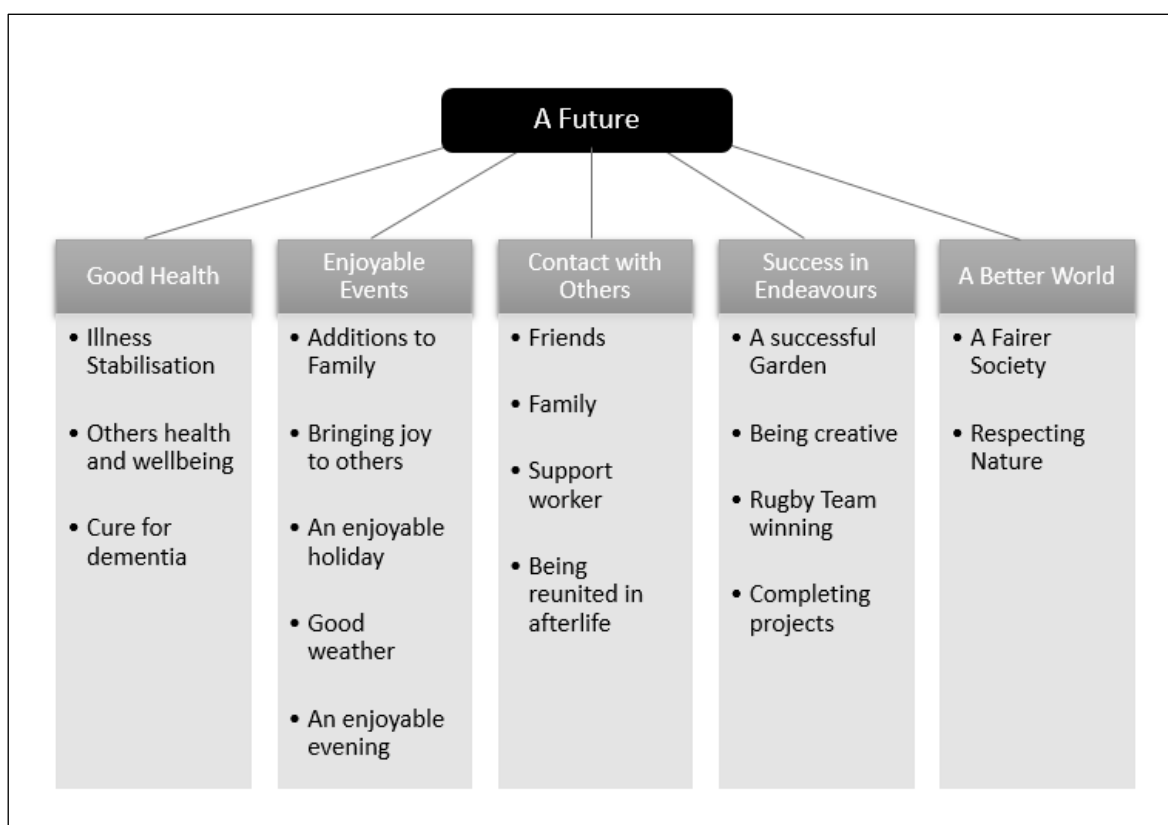


Figure 8 What participants hoped for

#### 4.2.1. Good health

Ann hoped that the symptoms of her dementia would stay the same and not worsen further, explaining that her wish was: “hopefully...to carry on...as I am” this was despite experiencing significant symptoms (including blindness); “I know I’m not as good at talking and...thinking...and stuff like that...I know I have had a turn...and...to be honest...I’m very happy to wake up every morning”. James expressed a similar wish; “*if this stays as good as it gets then I’ll take it thank you*”. He hoped that the medication he took was helping prevent decline but was not convinced that it would; “*I’m not sure...I I I’m hoping that it helps me but I don’t know*”. Matthew expressed a hope that the decline he expected would not happen any time soon; “*there will be bad times, but when they are bad...you know, like hopefully a while away*”. For Rachel seeing evidence that she was still able to do things that she enjoyed gave her hope; “*the fact that I was out, I was doing something that I really like it really gave me a hope that that’s another year that I’ve gone to you know the theatre and enjoyed something...you know?*”. Rachel spoke about her hope for some improvement in her symptoms, and was the only person to do this. Her hope was not for total recovery (cure) but for a small improvement such as the clearing of her head when she was having a difficult day; “*I sort of say mmm...please if there is a way of sort of increasing some brain cells here...you know...can I do it...or with the one’s I’ve got please don’t get more poorly*”. She felt this improvement was within her power, through meditation, rather than divine intervention.

Ann hoped that her husband would stop smoking as she worried about his health; “*he’d make me more hopeful if he would stop smoking!*”. In this way she moved the focus from her health to his. Richard hoped that his children would get on well in life, and hoped through them; “*well I want to...through the children...I want them all to get through to what they want to do*”. Ann also hoped for something other than herself; that a sickly tree given to her as a present would survive. Richard’s concern for others also extended to strangers, thinking about the people who lived in a tall tower he took a picture of on holiday; saying humorously “*I hope there’s a lift!*”.

Only one participant, Robert, spoke of his hope for a cure for dementia; “*perhaps they will sort of find a...a cure you never know*” and yet he did not say this with longing, or in the hope that he would be cured himself. None of the participants expressed a hope that they would be saved or that they had been wrongly diagnosed.



#### 4.2.2. Enjoyable events

Two people expressed hope for specific events to take place. Richard hoped that one day he might have grandchildren; *“we’re sort of expecting and hoping that we’re going to have the pitter patter of little feet”* and *“obviously we’re hoping...because they both want to have children that they’ll be successful”*. In a family addition of another kind he hoped to buy his son a puppy; *“that will be lovely...something to look forward to”*.

Richard looked forward with anticipation to things that would bring pleasure and joy to others, for example photographs he would share; *“so we’ll take these with us when we go to see them!”*, and the thought of a friend watching the DVD he had bought her; *“I think she’s looking forward to seeing it”*. Ann hoped, and looked forward to an upcoming holiday in Ireland with her husband. When asked what she hoped for she said; *“well I’m looking forward immediately to going on the boat over to Ireland”*. Ann spoke of a hope that the weather would be good on their holiday; *“when I used go on the...the boat...erm...I’d go running right to the back...and stand there forever!...but it’s probably going to be freezing!”*. Richard meanwhile saw signs of good weather coming; *“the sunset is the end of the day which promises good weather...good weather tomorrow”*. Ann enjoyed the live music at the last dementia café she attended, and hoped that next time they went she would have as good a time; *“I’m hoping if...we have it again...that it’ll be just as good”*.

#### 4.2.3. Contact with others

Richard had hope for seeing certain friends; *“I always look forward to speaking to him or seeing him”* and initiated interactions with others; *“I sent a message to my mate in Cornwall...saying this is something I found and I look forward to hearing your comments”*. Rachel similarly retained the confidence to reach out on social media, joining groups and making new friends, defying societal expectations of what someone with dementia should be capable of. Most people she met did not have dementia, and this was not a part of herself that she felt that she needed to reveal. Family were also very important to Rachel, but because most of her family lived abroad this unsettled her and she felt vulnerable; *“so I’m kind of on my own... it’s just hopeful that people will be around you? um...at different stages...or um...it’s hopeful that you can rely on your own family? um for different things?”*. Rachel’s support worker helped to compensate, and she looked forward to her visits; *“so...I’m always hopeful every week that I’ve got somebody that will come and that we sort of...we’re always laughing”*.

As a Christian, Richard spoke about his belief in the afterlife, and his hope of being reunited with loved ones; *“well I have a very sort of romantic belief that....and it came from my grandfather ...he was absolutely convinced that he would...in another place...he would meet them all again...and I think it’s a lovely thing to believe in...he said...when we go to heaven it will be full of dogs with the occasional lucky human...on a lead”*.

### 4.2.4. Success in endeavours

Ann and Robert, both keen gardeners, spoke about their hopes for their gardens thriving and invested a lot of time and energy. Robert for example looked forward to bulbs coming through in the spring; *“so that’s kind of the seasonal sort of planting now for...you know...you look to the new year sort of thing and bulbs about March...and they’ll start to come through; daffodils and that...”*. Richard’s interest in rugby meanwhile led to him hoping for something more competitive, that his team would win; *“I look forward to this rugby match this evening in the hope...that my side would win”* and he looked forward (albeit in the short-term) with anticipation; *“well let’s hope we go to bed on a high tonight”*. Ann described hoping against the odds that she would be able to take a good photograph of her dog with her disposable camera and she saw this as a challenge; *“I was hoping I’d get...there might be one there...oh! There he is! he’s just moved and...yeah there’s his head isn’t it...there he is...I think...yep”*. Richard also hoped to succeed in academic endeavours such as completing the biography and family tree he was writing, and did not see his dementia as presenting a barrier to completing these.

### 4.2.5. A better world

Many participants had hoped that others would be happy and saw a future world that was better because of their own efforts and endeavours. Rachel’s hopes were bigger still and she spoke of her hopes for humankind. She hoped that man would respect and live more in harmony with nature:

*“I’m just hopeful that one day we’ll realise that we can’t really control the weather? And we’ll start to think about...you know...um what we do when we do have those things happening? like those poor people in Scotland or wherever it was? Yorkshire or somewhere up north yeah with all the floods and everything and the government’s got to step in and sort of say yes we want new houses but...at the same time...you know if*

*they put um different ponds in...or waterways and and drainage around these areas um...that were decorative that people could use...rather than to um...take everything away". Rachel*

*She hoped that this would become a reality for future generations; "so that it will be different for my daughter...she's 22 now...and I do sort of worry about...n...not so much her and what she's going to be left with but her children...". Rachel also had hope that corporation activity could be broken up which she believed would bring about a fairer world:*

*"I'm quite hopeful that we will bring down eventually...maybe during my daughter's era...um a lot of the corporation activity? and things will become more fragmented and go back to smaller people...and smaller companies doing and providing more services than getting swept along with those that can advertise". Rachel*

### **4.3 Qualities of hope and associated concepts**

#### **4.3.1. Qualities of hope**

As has already been discussed, participants felt hopeful and that hope was important to them, but found that hope as a concept was hard to define. After analysing the transcript using the voice centred approach, the nature of hope for younger people with dementia began to come into focus. It was clear that hope had a number of qualities (see figure 9 on the following page); it was realistic rather than unobtainable, and could be either future, present or past orientated. Hope was part of an active process often involving goals, and was fluid, and potentially open to influence by others. Finally, hope could be a metaphor. Each of these themes are now discussed in turn.

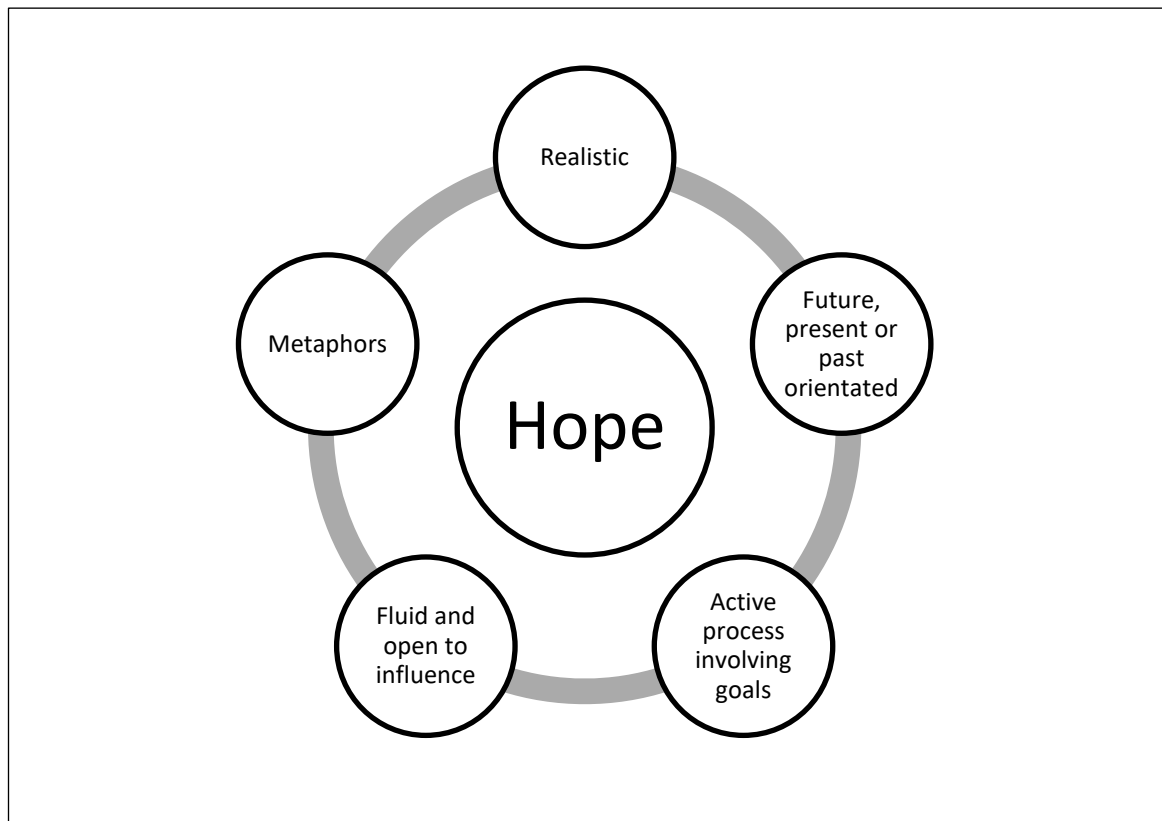


Figure 9 Qualities of hope

#### 4.3.1.1. Hope was realistic

Participants had modest hopes such as for good weather or an enjoyable holiday, and they were realistic about what was achievable within the context of dementia. Richard said of things he hoped for; *“well not if it’s hopeless...it’s got to be something that is possible”*. He gave climbing a mountain as an example of an unwise hope *“that doesn’t mean that I want to risk my life!...I have limitations”*. He also spoke about the failure of a hope to materialise as *“not being the end of the world”* indicating that hopes should be kept in perspective.

Hope did not seem to be based in denial for any of the participants. All understood that they had dementia and what their prognosis was. Robert spoke of the deterioration he expected; *“‘cause they call the the early-onset so um they obviously you know you deteriorate a bit I suppose as time goes on...”*. James had some doubts looking about whether his quality of life would be the same; *“I suppose sort of looking further forward in time erm when I get old...older even, um I don’t know whether my perceptions will be different. Do people say that? say er all of a sudden I have a problem and my,,,er and I get worse um...what will I do then? I’d still think that I could probably*

*play table tennis but I probably couldn't...or...would I be able to fill it with somebody something else? I don't know". Ann meanwhile said; "you know that you can't get better", and Rachel understood that meditating would not change the underlying problem; "and I think that feeding yourself positively isn't going to stop anything but..."*

Ann spoke about finding solace in other people with dementia, frequently attending a dementia café and organised walks, and she was clearly facing rather than running from her illness. Matthew did find this harder however and he found it upsetting being around other people with dementia, but had tried to engage. Ann appeared to have even considered her own funeral; *"when I die I don't want to be seeing any wood...I just want...flowers"*. This brought hope not despair. Like Robert, James and Rachel, planning ahead for when her illness had progressed (in her case converting the house) brought more rather than less hope. Like some of the others James planned for the future, he and his wife spoke of redesigning the garden for when he could no longer manage it himself; *"I'll I'll be supplying the labour um... yeah we've got that to do"*. While Rachel purposefully kept her belongings to a minimum so that there would be less for her daughter to deal with one day.

Hope did not seem to be related to symptom severity, and it could not be argued that participants had hope because symptoms were mild or absent. Rachel spoke at length about how her symptoms affected her, including this example of how going to the theatre could be problematic;

*"and it was really really good...but when we got in there I didn't realise that she'd seen it before and she just said to me... "mum...um...it's about to start now and just be aware that something might happen from behind you!" 'cause I'm not very good in dark and you know...and like the elephant comes down the aisle and the different things so it stopped me from screaming 'cuz I do scream...um when I'm focused on one thing and something else happens I'm a bit of a nightmare" Rachel.*

Also shopping could be difficult; *"and I've got my list...and I know what I'm getting...um but when it's with lots of people around and things and Christmas music and the whole...I'm just sort of like I don't know what I'm doing...I don't know where I am...and then I get like insidely embarrassed"*. James described frequent frustrations caused by his illness; *"I think sometimes...sometimes I just get so frustrated er with it"*. He spoke with sadness and a sense of loss about the impact dementia had had on his life; *"I used to manage teams...um...but that's all gone...I've not...you know that's under the carpet now"* but appeared to have accepted and made peace with his diagnosis and was able to find new goals; *"that's that's fine...er I suppose I've still got ambitions to do things"*.

Participants did not appear to experience unbridled optimism or seem to be ignoring or shutting out sadness from their lives as a way of coping. Their stories of hope and positivity were tempered with acknowledgment of darker emotions and stories. Richard for example told many humorous stories but also sad ones at times; such as when he found a dead foal while out walking. Matthew spoke of *“the darkness”* he was surrounded by after his diagnosis, and recent terrorist attacks in Paris very much occupied Rachel’s mind; *“yeah I mean I just got really stuck after the...the bombing and I couldn’t do anything”*.

### 4.3.1.2. Future, present or past orientated

Hope usually had a future orientation and was linked to anticipation. Ann for example said; *“hope is...thoughts of...you could either be like hoping to do something.”* Matthew, Rachel and Richard spoke of attaining goals and looking forward to seeing friends and family. Richard looked forward to future events, looking forward to seeing friends again, to completing a family tree, and to two friends watching DVD’s he had sent them. He also took pleasure from knowing that he had helped his children to get on the property market, knowing that their future was secure.

Richard took multiple pictures of sunsets which for him far from signifying an ending, symbolised something good yet to come; *“the sunset is the end of the day...promises good weather...good weather tomorrow”*. Rachel similarly saw the sunset as hopeful, seeing it as a prelude to sunrise. Robert hoped for a good growing season for his garden, for rain, good flowers, and for next year’s planning season. He also looked to the future when planning and carrying out his garden projects. James looked forward to going walking with his wife and the act of getting ready was a hopeful activity for him. He spoke of the importance of having enjoyable occasions to look forward to with their neighbours; *“three, three or four things they’ve said about doing, so...yep yeah that helps I think, yeah ev-even if it’s just a list of things we write down every now and again er you know it’s going to happen”*. Robert meanwhile looked forward to seeing his Consultant, and to upcoming family events.

Two participants spent significant amounts of time during their interviews reminiscing about past events, which seemed to bring them pleasure and hopeful feelings. Richard looked back at his time in a rowing team at University, at visiting steel works as a child, and told a series of anecdotes and stories collected through the years. Robert also looked back to his time at work which clearly gave him clear pleasure, at one point even showing old photographs of the gardens he had helped to create and maintain. He also told with great fondness the story of how he and his wife had met (his wife he said was a great source of hopefulness to him).

Hope could also found in the here and now for participants, in enjoyment and appreciation of the moment. Rachel said; *"I don't know whether people think...or give themselves time to think about being hopeful...it's more...I try and live in the moment...and not what happened last week or anything"*. For Ann hope also was in the here in *"things that are nice"* and in stimulating the senses *"everybody knows I love colours"*. Robert enjoyed spending time with his cat, as did Ann, Matthew and Richard their dogs, seeing them as entertainment as well as comfort, and all participants spoke of valuing time with their family.

#### 4.3.1.3. Active process often involving goals

Hope was usually something that participants actively sought. Richard said of a stranger's dog he had taken a photograph of; *"it's very rare for a dog not to catch your eye if you're looking for it"*. Art and culture was also very much something he sought out and looked for in architecture, art galleries and at music concerts. Ann spoke proudly of always being busy; *"'cuz we're always going somewhere aren't we?...as long as I'm sort of allowed...as long I'm....got something in me...I'll do things"*. Ann spoke about the importance of making an effort; *"well I always make an effort...like when (her husband) is talking with somebody I'll say 'who is this (husband's name)'" and I can have a conversation with them...you know...just little short conversation and that makes me feel good...you know...because when I was started h...with this I thought I'd never come out of the house...do you know what I mean?"*. The voice-centred model helps to reveal that Ann was exceeding her own expectations, having anticipated that someone with dementia would be significantly less autonomous, and that she took pleasure in demonstrating her abilities again and again. She made the effort to go to the dementia café, a source of hope for her; *"well we go to all the meetings...and stuff...and um...things like that, so that's really nice yeah"* and she also enjoyed going swimming; *"I swim now...yeah...I can't wait for my son in law to come home"*. Rachel felt strongly that hope was something that had to be worked for and came from within; *"so you've got to create your own hope I think you've just got to create your own hope"*. Rachel spoke of the importance of stretching yourself and going out of your comfort zone; *"this week it was about portraits and everybody sort of went...oooh I don't know if I can do that...I don't think I can do that...but then after five minutes everyone was then doing it! some people had help...some people didn't have help and everybody enjoyed it"*. Ann said that nothing held her back and even spoke of a wish to go wing walking for charity; *"goodness I've done all sorts of things...yeah...and I wanted to do a walk...on a plane...well not walk on it...they clamp you on it...for the um...ah...what's it called...(to husband) I was just saying...nothing holds me back does it?"*.

Richard seemed to be able to see the hope in potentially negative situations, choosing optimism. He described negative events such as when a friend in Sri Lanka was repeatedly frisked at security checks, holding up the group, and turned this into a joke with the man about rubber gloves being next; *“he was chortling about it all the way home and it was really good fun!”*. He also spoke of rain keeping the grass nice, and when a drought on holiday meant they could not see all of the river, he focused on the fact that this meant the boat was less crowded and the financial incentive this brought (they were given a discount off a future holiday).

Robert was perhaps the most goal directed of the participants, continually setting himself goals in the garden, both small and large to achieve, and these brought about a sense of hope. James similarly enjoyed having goals to think about rather than dwelling on his situation; *“yeah I don’t sort of say well damn it it’s me...erm it...I I tend to think...well yeah ok um...there’s a list of jobs I’ve got to do...today even if it’s just chopping wood in the garage...um...and...we we always seem to have something on don’t we?”*. Keeping busy also helped to keep James feeling positive; *“it’s just um er...I suppose just being very busy it helps me to sort of keep on top of my depression if there is such a thing...and I don’t feel depressed...um, I’m just generally I just sort of shrug my shoulders and oh well”*. For him the turning point in his despair after receiving his diagnosis was going on holiday; *“I suppose what we’ve done is we’ve made ourselves so busy...going to Australia”*.

Hope was often part of an active process involving physical labour, that participants had to physically work hard to obtain. Robert dug trenches, re-worked borders, scarified the grass and renovated his shed. Mathew’s cycling and interest in keeping fit was similarly physically demanding, as was his regular walking. James enjoyed playing table tennis competitively, and Ann enjoyed attending the local ‘walk and talk’ group, and visiting gardens. Richard also enjoyed walking with his dogs and enjoyed pushing himself when on holiday, getting to the top of a steep hill.

### 4.3.1.4. Fluid and potentially open to influence

Despite mainly being hopeful, Ann hinted that her hope was sometimes fluid; *“I do have my moments”*. Richard felt that his hope was also affected by whether or not his rugby team did well but he was able to his hopes in context; *“but er...it’s not the end of the world! you’d be in a bad way if you were suicidal every time that they lose!”*. Watching the news decreased Rachel’s level of hope; *“oh! yes that’s why I try not to”* but not necessarily for the reasons one might expect; *“because um...wherever I’ve lived in the world...which is quite a few places...the news has always been very different to how we broadcast BBC news...it’s very...this is what’s happening here...and*



*you know...this is all you need to worry about if you see what I'm saying?...I would like to see BBC for example um just do a quick touch on...this is what's happened in Europe today".* Subjects of most photographs had highly changeable and transitory qualities; sunshine, sunsets and flowers blooming for example.

Matthew's hope was adversely affected when he first received his diagnosis, having since recovered some of his hope; *"I think we've come out of the...the darkness to, to a certain extent".* James felt that his hope had not really been affected by his diagnosis; *"I think it's all I think it on a level"* as was the case with Ann; *"I don't think I have any more or less (hope)...I just...go along with it".*

Rachel described to how others could enable her hope, and many of her photographs were taken in the company of others; at the theatre, and on a trip to the woods. This was particularly marked compared to the other participants. She hoped that her family will be in touch, using social networking to bring hopeful feelings; *"I use Facebook um....um...for for family and friends um and for sort of meeting um e-friends if you get what I mean? er just people who are like minded and share jokes or stuff like that".* A slimming club facilitator inspired hope in her; *"and she can just you know really spur everybody on",* as did her support worker:

*"She's very good 'cuz she reads me...each time...so sometimes she'll sort of say (claps hands) "right what we doing today?" and really motivate me to want to go to a garden centre and have a coffee and something simple? but do you know what I mean? Other times we'll sit and we'll write poetry or something...we've got a book hopefully coming out in um...March I think".* Rachel

Rachel also shared her own hope with others. She taught other people with dementia to make mosaics; *"because I do so many mosaics I thought it would just be nice to share it? and everybody's really getting into it now".* She sold these sometimes, and passed on her hope with them; *"yeah...and when I create something like that and someone goes to a craft fayre and buys it 'cuz they love it...it's knowing that you've passed something on...giving somebody else pleasure".* She also gave away a swing from her garden to a good cause:

*"Yeah it's about doing something good...and um...er...you know this lady...um and she just got a new baby...and she was just looking forward to giving it a spray paint and putting some cushions on it...so that she could sit outside with her baby? and stuff...and I'd rather give it away so it can be used...and...um...be appreciated."* Rachel

Rachel was aware of her limitations and that pathway thinking (planning how to achieve something) was particularly hard for her because of the nature of her symptoms. She hoped through others therefore, who were able to provide the pathways to achieving goals for themselves.

### 4.3.1.5. Metaphors for hope; being outside

Several metaphors for hope were discernible in participants' photographs and accounts, the majority of which involved being outside and close to the natural world. Metaphors are something which Brown and Gilligan (1993) have highlighted as being highly significant in voice centred relational analysis, helping with interpreting 'indirect discourse' which voices can be *"deeply encoded, deliberately or unwittingly opaque"* (Brown & Gilligan, 1993, p15).

#### **Sun**

Sunshine was a powerful metaphor for hope and a recurrent theme in participant's accounts. Ann relished being outside; *"I love sitting out in the sun"* and when asked if it makes her feel hopeful she explained how much it meant to her; *"oh goodness yes!...it's like before you came I...'cuz it's not that warm out there really...but there's patches of it so I was wandering around just trying to find...where the...sun is! ...you know you get it on your face and you just stop...you know...it's just really nice..."*. Ann sought out the sun in the same way that she worked to maintain her hope, she was on personal terms with it (*"the old sun"*) with hope, happiness and sunshine meaning the same thing. Sunset, and the darkness that followed it was a frightening time for Rachel, but a hopeful time as well as she hung on to the last bits of daylight and looked forward to the sun rising again the next day.

#### **Rain**

Sunshine was often tempered by the rain which could disrupt plans and holidays, reducing hope. Rachel saw flooding as being a warning to humanity that better care should be taken of the environment and better care when building housing. But as with many other participants, she was able to turn this around into a hope for humanity instead. Richard was able to look on the bright side, that rain helped to keep the grass nice, and Robert had developed an elaborate system for collecting and measuring the rain, a hobby of his; *"this is the rain gauge so I know...we've had a lot of (rain) I've got two of them...one either side, yeah...I know it's mad, but there you go"*.

#### **Rainbows**

Perhaps inevitably, given the above, rainbows were something that Rachel adored and they held special significance for her:

*“I love rainbows...it is a symbol of hope...absolutely. They also had a magical quality; I love rainbows they’re always...you know it’s fantasy and all the rest of it pot of gold at the end of the rainbow and...you know...sort of unicorns prancing and all that sort of silly nonsense do you know what I mean?”* Rachel

The rainbow in a photograph she took was hard to see, but she had spotted it and seen something beautiful amongst the rain; *“when it’s rained...and then the sun’s come out and everything’s all fresh...invigorated”*.

### ***Garden growing***

Gardening was a big theme for Ann and Robert, both passionate gardeners, and for James who had an allotment. Having worked as a professional gardener for most of his life, continuing to carry out projects in the garden was tied in with Robert’s self-esteem, and was an enormous source of hope and satisfaction for him. The garden had become his hope and his obsession. For Ann being amongst greenery was uplifting and she knew the plants in her garden intimately, being able to identify them by touch when she lost her eyesight. For her the garden was also a symbol of hope, she said simply; *“that’s hope...you know...with the garden growing and everything”*.

### ***Seasons***

Related to the idea of nature representing hope, seasons can reflect hope’s changeable nature. For James winter was a time when he couldn’t do much with his allotment and he described it as looking ‘grim’ at this time. Matthew also described the family’s favourite walking spot being there for them whatever the season; *“and every season...it’s always there”*. Seasonal planting and autumn colours were important to Robert:

*“You’d have um spring flowers in there in the summer and there in this time of year polyanthus and um er bulbs um daffodils which will flower again next year...so that’s the seasonal sort of planting now”*. Robert

He also spoke of looking forward to the new shoots of spring; *“you look to the new year sort of thing and bulbs about March...and they’ll start to come through; daffodils and that”*.

#### 4.3.1.5. Metaphors for hope; resilience in the face of adversity

##### ***Fire as renewal***

Rachel took photographs of a local historic building which had been badly damaged by fire and was covered in scaffolding, stating that this brought her hope. On the face of things this seemed an unusual choice. Rachel however was able to see beyond the sadness and destruction, finding meaning and hope. For her the building symbolised renewal, both the physical renewal of the building as work continued to restore it, and her renewed sense of faith in humanity knowing that people felt it to be worth saving and were taking the time to do this; *“Last year it happened...and um this year...um...still...fixing it so you know it’s like although it’s really old you know they’re going to restore it so that when all that stuff comes down it’ll look as it did before the fire...so it’s kind of like a rebirth if you see what I’m saying...because it would be an ideal opportunity for them to up...up do...do it up”*.

##### ***Weathering storms***

Like fire, the wind was another destructive force that could wreak havoc and despair. Robert spoke of a historic chapel that he helped to save during the hurricane of 1987, climbing onto the roof to help secure the stone cross that had come loose. Simply recalling the event seemed to bring him great joy and satisfaction:

*“He said...do you want to come to the roof? And I said ‘oh yeah!’ he said he said I asked [name omitted] to come he said, but he’s frightened of heights! so I went with him right to the top of the roof! And there was the cross! And you stand...you stand...(pulls back chair) there! And...you know...it’s you know, miles high!”. Robert*

The wind could threaten some of the more fragile stalks and flowers in Ann’s garden. She took pictures of a particular white, delicate looking flower which brought her hope, and which despite appearances was incredibly resilient:

*“Oh the wind flowers...oh they’re beautiful...you must go out and have a look at them they’re the prettiest things in the world that’s...it’s the...um...common name for it I can’t think what it is but it’s because they just...they don’t break...they literally in the wind they just (uses arms to mimic swaying) DANCE!”. Ann*

#### 4.4 Associated Concepts

In addition to the qualities of hope described above it was found that hope also had number of inter-related concepts (see figure 10 below). Hope was hard to distinguish from other positive emotions like happiness, and also from the concept of resilience. A third strong theme was adversity, with hope appearing to often spring from, rather than being weakened by adversity.

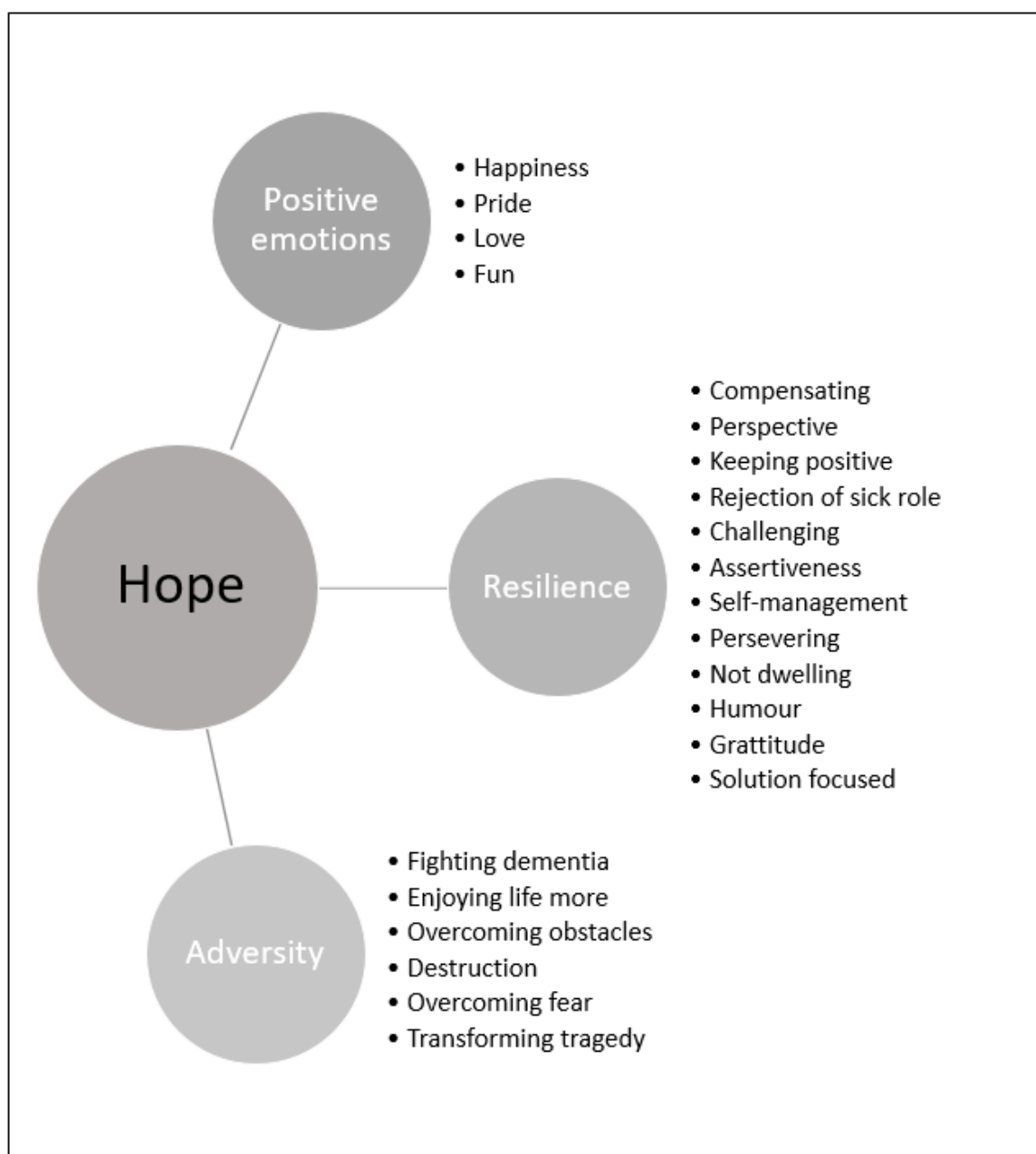


Figure 10 Hope and associated concepts

#### 4.4.1. Positive emotions

##### **Happiness**

Many participants connected hopeful feelings with other positive emotions, particularly Ann whose narrative was very descriptive frequently contained discussion of emotions. Matthew said of the task given to him; *"in general it has been quite hard to unpick the difference between hope and happiness"*. When asked if he was a hopeful person he had replied; *"I feel, I feel...quite happy myself, and that's a really bland expression isn't it? But I'm...(exhales) I just...you know...sort of quite happy...really...you know, I'm really happy that you know, where we live, and the friends we've got and the family...and that fact that we can go on holidays and stuff like that...I really really value them"*. For Richard hope was the same as happiness, *"a smile"*, *"a positive"* and *"a plus"* and he used all of these words interchangeably. For Rachel hope similarly involved enjoyment and laughter; *"so...I'm always hopeful every week that I've got somebody that will come and that we sort of...we're always laughing and doing some different things"*. The subject of one of James' photographs was one of his grandchildren; *"oh my Lord!! It's (his name) That is a cracker!...I mean look at that grin!...bless him!"* and he explained why this made him hopeful; *"they're genuinely happy to see us"*. Another of his photographs was of a friend, and again happiness seemed the same as hope to him; *"he's just got a real grin on his face there and...I'm here...and that's lovely...but I think that's good because it's...it's...his face is so happy there"*.

##### **Pride**

Several participants spoke of their pride. Richard spoke about his pride at having belonged to the rowing team at university and spoke about a photograph of this that brought him joy. He said of that day *"we didn't do terribly well by the way"* but to him this didn't matter it was the emotion that brought hopeful feelings. He was also proud of his volunteer driving; *"the people I am driving are very grateful...almost without exception I come away thinking I'm glad that I was able to help this person"*. Making friends on holiday also brought about pride and hopeful feelings; *"and they didn't seem to know what to do and I said 'here...please sit down with us' and so on...and that started a friendship that goes on still...they are very elderly...well into their 90's..."* *"they are very sweet people and I'm very...I'm rather proud that we made friends."* Robert took pride in the gardening projects he undertook, and when his flowers did well this brought pride and a sense of accomplishment. Similarly he took pride in recounting the celebrities that he met over the years through his work. Rachel also took obvious pride in her poetry, photography, and mosaics, although she did not communicate this pride so overtly as the men.

## Love

Love and connection to others was also connected to hope for Ann. Hope for her was; *“how I thought of people I knew...and things like that”*. Rachel described a mosaic that she made in the shape of a heart, symbolising love; *“yeah...and you know a nice heart and love and and people around you and just creating something yeah...yeah er and showing your family love...and showing you know just unconditional love”*. Of a second mosaic, which symbolised hope for her she said; *“and that’s the love...you can see it...it’s got hearts and crosses and the red white and blue and everything”*.

## Fun

The voice-centred relational method revealed that fun featured in participant’s stories. Ann spoke of enjoying swimming at a swimming pool with a wave machine; *“oh! it’s brilliant, it’s really good fun...it’s great there”*. She loved attending an art group for a similar reason; *“but it was good fun...we had really good fun...all glues and paints and all sort and um...stuff like that”*. One of her photographs was of her smiling and laughing (she explained that she had found a rude looking plant), and she told funny stories about thinking leaves touching her head were spiders, as well as one about a spider that jumped out at her in the museum. Ann said of her dog; *“I love him...he’s funny”*, and he kept her amused:

*“because he loves...because there’s a seat there and he thinks that’s his seat!” and; “well he’s funny because he literally...literally...his legs are akimbo...and you know...he sits in the whole chair...like an old man!”*. Ann

Robert spoke animatedly of how his cat brought him hope when he played with him; *“I just roll them up you see and...(laughs) and I throw them up the stairs...and he’s there!! And he’s like a footballer!”*.

Richard said of his dogs *“it’s quite good fun watching them”* and enjoyed watching the horses in the field for a similar reason; *“it’s rather fun”*. Many of Richard’s friends made him hopeful as they had a good sense of humour. He said of one friend; *“he’s absolutely fantastically good fun”*, *“he’s a huge plus...just even thinking about him...he’s really good fun”*. Of friends he made on holiday he said; *“good fun weren’t they?”* and of others; *“they’re always up for it”* and *“and he was chortling all the way home it was really good fun!”*. He laughed as he told a story about sending a friend the ‘Babe’ DVD under slightly false pretences; *“I think it’s absolutely gloriously funny”* and he

explained that humour was still a strength that he had; *“joking and so on that’s still intact...thank God”*. Richard gained hope during an unusual sermon at his church; *“the rector...he is absolutely priceless...he gave a...last Christmas he er...at midnight he did a sermon about feet...and it was priceless...it was really good so I liked that...and I think he got it immediately...this is a place where people have fun”*.

While James’ grandchildren brought fun and an element of chaos to his life which he loved; *“it’s really good to see them in a pack...you know ‘cuz all of a sudden the boys in particular they they come in here and they empty all the boxes and they go upstairs and they sort everything out and then they go and we think...oh...crikey...the house is...it’s upside down yeah exactly...and then they’re gone...(makes wind noises) yeah because yeah generally we keep the house you know...sort of reasonably tidy...but they know the spots...they know the places...so they’ll just pick something up...arghh!! empty that...argh!! um”*.

### 4.4.2. Resilience

#### ***Compensating***

Ann was the only person who spoke of compensating for her difficulties, perhaps because her vision loss affected her so greatly. For her this was of great importance. She demonstrated a great deal of resilience when dealing with her loss of sight even when it prevented her from seeing the plants she loved so much; *“obviously now...because I can’t see too good...I just sort of like feel for them...it’s just nice to feel them really...it’s just as good...but it’s different...that’s all it is really”*. She spoke about compensating by developing a heightened sense of touch, preparing for this loss; *“I think probably, you know, I was getting myself ready for that.”* In this way she was able to reframe her loss, and kept focus on her strengths.

#### ***Perspective***

Ann was able to look to the bigger picture, seeing beyond her impairment; *“I have more...good things in my life than bad things...do you know what I mean”*. James also does not let his illness take over his life; *“my problem is...just another irritant...so yeah so yes I get I get annoyed, but I mean that’s...hey”* and also seeks to normalise his illness by recognising that dementia is common and he is not alone; *“there’s a lot of people...how many people have got dementia I wonder?”*. Matthew goes one step further and speaks about how his illness has changed his perspective on



life; *“it’s funny because things like this...you come to, you know, enjoy them more because you know, after the nastiness and all that stuff you just think...these are beautiful places. When went to er, you know, last week and we arrived at...um...thingy’s house...and it was this bea...and I...I...I...so things like that they live in this beautiful valley and things like that I just find it really really sort of...yeah...uplifting”* Elsewhere he also describes himself as being less cynical since his illness began.

### ***Keeping positive***

All participants when interviewed had a striking positivity about life. Rachel expressed this overtly; *“I always try and be hopeful and optimistic rather than sad”*, as did Ann, who explained that this was just as much for others’ sakes; *“I think the worst thing...if I was whinging and...mythering and...stuff like that...do you know what I mean? ...erm um...that would be awful...yeah...I must keep up my...you know...’cuz I’ve always been a happy person”*. The Voice-centred model reveals that there was an element of obligation to be positive in Rachel and Ann’s accounts, although it is unclear where this pressure comes from, whether it is part of their personalities, a wish not to be a burden to loved ones, or if it is related to societal pressures to be ‘brave’ when living with illness.

### ***Rejection of sick role***

None of the participants appeared to have adopted the ‘sick role’, that is a pattern of behaviour where the person behaves as if they are ill, in line with the expectations placed on them by others (Parsons, 1951), and in fact as mentioned above, they seemed to actively resist this. Nor did they display evidence of what Brody (1971) called ‘excess disability’, that is functioning at a level below what can be explained by their dementia. Robert however enjoyed seeing his Consultant, and Rachel looked forward to seeing her support worker, but they did not focus on their deficits or see themselves as incapable. Rachel had days when her symptoms made life difficult; *“some days...my brain just doesn’t want to function...in the way that I want it to function so I let it do what it wants to do”*. But this letting her brain ‘do what it wanted’ was not about giving up, but conserving energy and regrouping; *“and then at some stage during the day or it might be some food...or it might be something and then I think well actually...I’m going to go for a walk you know?”*. Keeping active and busy helped her to see beyond her diagnosis; *“once I get out there and see the...then...I’m not thinking about the dementia but I’m doing something so it’s not concentrating on it all the time”*. Rachel showed great determination to be as independent as possible,

persevering, and when that was not effective she was prepared to change the goal rather than give up; *“even if it’s not carry on...do something else”*. Rachel also helped others to develop this spirit; *“she said to me the other day...ah...er I don’t know I’m going to stop driving, and I know that you get to the point where you know that you need to stop driving but that’s just one small step it don’t mean to say she can’t get on the train”*.

Robert and Rachel enjoyed trying to better their scores on the Mini Mental State Exam (a cognitive test) when it was carried out by professionals who were using it to monitor any decline in their cognition. Robert described coaching himself over long periods of time; *“as the months go on and that I try to think about...you know you’ve got who won Wimbledon and various things like (laughs) and I try to think to myself...who...and you know and recall things and various things like that”*. Rachel also felt compelled to work at keeping her score up, and to protect herself from, rather than take on a dementia identity; *“I don’t know there’s this self-preservation thing inside you you do try and...you know if I had to do it again I know that I’ll be slower...but I’ll be calculating all the time...to get it right...whereas if I really had to give that answer straight away I wouldn’t get it right d’ya know what I mean?”*. Rachel also described how in frustration she fought the sedating medication she was given in Spain; *“I was feeling as if I was being suppressed...which was the drugs...and I was trying to fight out of it all the time”*. Professionals perceived her to have challenging behaviour (she said at one point that she was also diagnosed with a Personality Disorder) and Rachel looking back said herself; *“I had all of this really bad behaviour going on um...but it wasn’t all me...do you see what I’m saying? And then I got frustrated.”* But interestingly Rachel’s behaviour could be interpreted in a different way, as an expression of hope, and a rejection of the sick role assigned to her.

### **Challenging**

Rachel was the only person who directly challenged how dementia was portrayed, when she spoke about a recent film where the progression of the main character’s illness was shown as rapid. For her how dementia was portrayed was very important to her and her own sense of self, which the voice-centred relational method revealed. She said:

*“It was nice that someone was trying to get a point over but it all happened so quickly and so um...um...it’s reduced the whole thing yeah and I think that some of their story lines could have been different so that it was like three years had passed...or a year had passed or...’cuz I’ve not met anybody yet...um...with...early onset...um that has been*

*given a diagnosis and then died straight away I'm not saying that can't happen...and I'm sure it does". Rachel*

She was herself featured in a newspaper article, which she discussed, and she questioned how she was portrayed; *"I don't think that they were that sympathetic".* She was not only physically altered to appear unlike herself in the accompanying photograph; *"because they put a lot of makeup...they put my hair up and different things...and um...yeah and I wasn't wearing my glasses...so like my eyes...yeah I couldn't...I didn't know what was going on d'ya know what I mean?"* but she looked anxious, confused and vulnerable. This was in sharp contrast to the independent, fun-loving and articulate woman who took part in the interview. She was unhappy with the article stating that she has Alzheimer's Disease (she has vascular dementia) because of the way it pigeon-holed her:

*"I prefer to say early onset dementia because um it gives a different impression? ...because I'm quite sort of able...and if then people are reading 'oh she's got Alzheimer's' that's when you get people sort of saying stuff like "oh well are you sure you've got it 'cuz you don't act like it" 'cuz' they're expecting me to be...in a chair...you know...in the corner of a room or something". Rachel*

### **Assertiveness**

Participants were all assertive in their own ways. Rachel was perhaps the most open about her diagnosis however, calling on help when she required it. Before attending a slimming group, she called the group leader on the telephone and disclosed her illness in an open way, which enabled her to be better supported; *"...and that's helps me a lot...do you know what I mean? and she was really good and um she said "well my name's (omitted) and we have two groups, and come and sit at the front and and I will go through everything".* She was equally open at supermarket checkouts when shopping alone, a place where she can feel easily flustered; *"I just say...look...I might not look like it but I have dementia...**please be patient**".*

### **Self-management**

Rachel, the only one of the participants to live alone, was very organised and tried to keep independent:

*"I've got this strategy for how I can do things and I keep trying to keep that going if you see what I'm saying some days it just doesn't happen and there's nothing in my head and...you know the whole kit and caboodle...but then the next day I'll just see a reminder and...and then remember or...I've got these blackboards around and um they um...keep me on track". Rachel*

She also uses mediation to reduce her symptoms self-manage;

*"I sort of got into sort of meditation and stuff...probably about ten years before all of this? so I've learned how to quiet my mind when things are just totally so wrong and I'll just wait until...I'll sit until...um either a voice in my head or a picture comes up um and I'll go yeah alright...you know". Rachel*

### **Persevering**

Participants seemed to be able to keep going despite setbacks. Richard described his determination and competitiveness; *"I hate...I hate giving in....I don't mind losing...that's different...but er...but giving up is...yeah".* It takes Rachel several days to book train and theatre tickets on the internet as a surprise for her daughter, but she perseveres and her daughter is amazed that she has been able to accomplish this. She also spends months figuring out the right spot to set up her mosaic table when the shed becomes too cold to work in; *"I mean it's been since December I've been thinking how...how can I do this? And I just keep trying different things do you know what I mean?".* She took a picture of the table; *"that's obviously when I was sitting out in the porch...to show that I did keep trying!"*.

### **Not dwelling**

Connected to the concepts of 'rejection of the sick role' and 'seeing positives', none of the participants seemed to dwell on their dementia. Interestingly from the outside this might be seen as denial (or were their illnesses further progressed a lack of insight) but it was in fact very much a conscious decision to not lose hope. James said; *"that's the bit I don't really dwell on because it's....there's so many other things to do...that's right because and in fact I don't I don't really dwell on...the future or or another diagnosis or or if there is another one".* Rachel spoke of not concentrating on what she can't do as this would destroy her hope; *"if I was that sort of person then I don't think that I would be going forward with anything".* Matthew meanwhile very much

took the attitude of 'Carpe Diem' (seizing the day); *"there's no point not to, no reason not to enjoy it now because you might not have an opportunity! to do it again you know?"*.

### **Humour**

As has already been discussed, many participants equated hope with happiness, fun and humour. James and Ann can also be seen using humour as a strategy, perhaps to invoke hopeful feelings at times when their hope is threatened. When James' wife points out the errors he makes when asked to draw a clock face (part of cognitive testing) he responds with humour; *"it's quite simply though you just go get a watch that goes backwards!"*. Again this seems to be a conscious strategy, not a lack of understanding on his part. Ann similarly perhaps feels vulnerable talking about her loss of sight and the impact of this on her ability to do her beloved gardening. She explains, with humour, and some self-depreciation how she stays involved; *"I still go down there...and ju...(starts laughing) and murder the plants!...as long as I can get hold of a, a plant, I'm, I'm happy"*.

### **Gratitude**

James describes himself as both lucky; *"um...I'm very lucky that I've got a network...aren't I?"* and fortunate; *"we're fortunate that you know, we do have money that we can go on holidays"*. Rachel also expresses gratitude which helps her to stay positive; *"I know that I haven't had a TIA for two years and all the mm...medication I take is preventative and so that's why I feel lucky and humbled...that er the UK took a different take on it if you see what I'm saying?"*. Richard was grateful for small mercies, being able to see the positives in potentially negative situations, like seeing the rain as being good for the grass, and focusing on his strengths; like his sense of humour rather than deficits.

### **Solution focused**

All participants, especially the men, showed resilience in that they overcame obstacles in life and kept going. James spoke eloquently about a related concept; searching for solutions. This was an approach he leaned elsewhere in his life and was able to apply to his current situation; *"yeah I was...in my job I was very meticulous and I I would um...I think um...always always looking for solutions I think"*. This helped him to not only continue with playing his table tennis, but with

winning; *“sometimes I get to a point where I say er....I can beat these guys...and I do...and it surprises me...um but I think that’s...that’s you know, just my nature really...um...I treat everything as a problem I suppose...yeah probably do...I would normally overcome most things”*. James uses a fellow player as an example of how adversity could be overcome; *“when I play table tennis there’s um...there’s a couple of guys one’s got a withered hand and he actually throws the ball up with his withered hand and serves with the other one...yeah...so...I suppose people do find...they do find ways round these things you know they don’t let it stop them”*.

#### **4.4.3. Created by adversity**

Hope was commonly spoken about within the context of adversity, and not just with regards to their dementia. Hope seemed to spring directly from hardships of all kinds.

#### ***Fighting dementia***

Adversity was something all participants faced in the form of their dementia, and each seemed to be fighting back to reclaim their lives. While many photographs participants took were most commonly of pleasant, relaxing subjects such as seeing friends and enjoying nature, beneath the surface the stories they told were of battling to continue to live a normal life. Simply leaving the house for example was something that Ann thought she would never be able to do. Many spoke of the thrill of being on holiday, and Richard of climbing up to a castle, high up a steep hill, alone and on a rough path; *“not many of us actually got to the very top...I was absolutely determined I was not going to be beaten by it...it would have been so easy to say...oh no...I’m not going to do that”*. Ann even spoke about her wish to do a wing-walk for charity, not something that most people would associate with someone with dementia. In this way she enjoyed challenging societal perceptions of people with dementia. She also spoke of the surprise that many staff in clothes shops had when she went shopping with her husband *“well he shows...he shows...he shows them his carer...his carer one (card)...and sometimes they...they ask what...what’s...you know...what’s wrong with me...and...he just says and you know nine times out of ten they just can’t believe it! you know? Because there’s somebody...like...looking like normal...and coming in to buy dresses although I’ve got dementia...I mean...you know (in a joking voice)...how dare they!! (come and buy clothes)”*.

**Enjoying life more**

Matthew spoke of his dementia giving him perspective; *“it’s funny because things like this...you come to, you know, enjoy them more because you know, after the nastiness and all that stuff you just think...(...) these are beautiful places”*. He wrote about spending more quality time with his family; *“having time to appreciate the countryside in the area around where I live and experiencing the seasons. It is new and valuable to have this time”*. He spoke about appreciating things more and being less cynical; *“yeah...oh definitely...definitely...and you know, little things like I think I’m probably, I think I’m less...cynical...I used to be quite cynical...about things...I don’t think I am as much as I was...and I think I am a bit, probably a bit nicer to people...as well”*. He was keen to stress that it was important not to go too far however and to see the world through rose-tinted glasses; *“you’re not going to say...hey everyone it’s great and all that stuff” and he had some reservations about being expected to be hopeful all the time; “you can’t...you can’t jam it down someone’s throat...it’s not as bad as you think you know!!! De-de-de-de!!! because sometimes oh we have...we have a meeting on Wednesday!”*.

**Overcoming obstacles**

For Robert, hope involved overcoming adversity in the shape of bad weather, but also sometimes involved risk to personal safety. He recalled (with delight) dangling his boss by the feet above a waterway as they tried to free up a jammed gate. Rachel described how she uses a strategy to clear her mind and refocus when out shopping; *“and um, just try and ground myself by maybe going for a coffee...and I might have only had one ten minutes earlier but and you know...and it’s just like to sort of like...you know like ok...where is the car...? you know and um we’re just sort of going to like walk with our eyes closed and get in the car and once you’re in the car then we’re just going to physically gonna turn around and go home do y’a know what I mean? And stuff like that because otherwise I’m just like I’m away...and I do stupid things...I do the most ridiculous things, do you know what I mean?”*. She employs a different strategy to overcome feelings of guilt about having bought too much food; *“I called him down one day...and I just had to give away all this stuff...do you know what I mean? especially like all the biscuits and all that sort of stuff but I bought food for the freezer that wasn’t food that I would generally eat? And stuff and so I just gave it all to him because that’s my solution, because that’s all it was doing was getting me down...because I didn’t want to go shopping again because I’d got all this food”*.

**Created by adversity; Regeneration**

## Chapter 4

A little unexpectedly, hope involved considerable destruction at times. Robert's described the process of scarifying the grass, a hope inducing activity for him; *"yeah I scarified all the...well it gets all the thatch out all the dead grass? And then you sort of put...er this time of year you sort of put what I call an Autumn feed on...which is low in Nitrogen whereas the spring and summer one is high in...nitrogen where you get more growth"*. As his wife pointed out, this was a process that often left onlookers thinking; *"well you've made a right mess of that"*, but actually it facilitated regeneration. Similarly he aerated the ground with a spiker, which enabled the grass to return healthier and stronger. His garden projects involved transforming areas, from boarders, to revamping the shed which was falling apart when he inherited it, turning it into a beach hut style feature.

Rachel also found hope amidst the darkness which she feared and amid the devastation of the fire in her local town (section on metaphors; fire as rebirth, p78). Where many people might see fire as only devastation, she focused on the effort people made to rebuild and how this gave her hope for the world. She found rain invigorating; *"when it's rained...and then the sun's come out and everything's all fresh...invigorated"* and spoke about being "obsessed" with the 'circle of life' (regeneration) theme central to the film 'The Lion King'. She spoke of her love of nature:

*"I just feel hopeful when I'm able to get out and go to like the woods and walk and be amongst nature? it just sort of gives me a sense of hope...watching everything regenerate...and um...well just the way that nature works really"*. Rachel

Rachel also saw hope in the gentrification of a city centre; *"because it last time I went there it was really quite run down...um...and how it could be sort of lifted up"*.

### ***Created by adversity; Overcoming fear***

Fear, also enabled Rachel's hope. The darkness bothered her; *"it's a time for me that when the sun goes down um it...becomes very...um...I need light to function...do you know what I mean? I don't like it when it...when the sun has actually set and then...you've got all of those hours"* yet she took a photograph of the sunset, because it also brought her hope of sunrise. She took a picture of the snow (again something she dislikes) as she had been able to transform this fear into something positive, a work of art; *"there was a threat of snow...do you know what I mean? I was hopeful at being able to be creative in the snow 'cuz I really don't like it...so I might as well do something that...do you know what I mean?"*.



***Created by adversity; Transforming tragedy***

Like with the snow, and the fire at the hotel, Rachel was able to transform the tragedy of the recent Paris bombings into an outpouring of love:

*“It’s all red white and blue and it’s got a little heart and a little cross in it? I did it in the French colours ‘cuz when things like that happen I find it very difficult to express myself? because I’m so sad inside? so um...it’s just something that we need a lot more of so er...apart from it being a mosaic...love for me is very important with...you know the vagrant on the street or the homeless person to...some Granny living on her own and not ever seeing anybody”.* Rachel

## **4.5        Where hope comes from**

The participant’s photographs, supported by the discussion, revealed much about what hope meant to them. Higher order themes generated suggested that hope came from; appreciating surroundings, keeping connected, taking action, and drawing on internal resources. There were also a large number of sub-themes as shown in figure 11 on the following page, and in appendix I. Together the themes symbolised ‘defying dementia’, the ability to live well despite their illness.

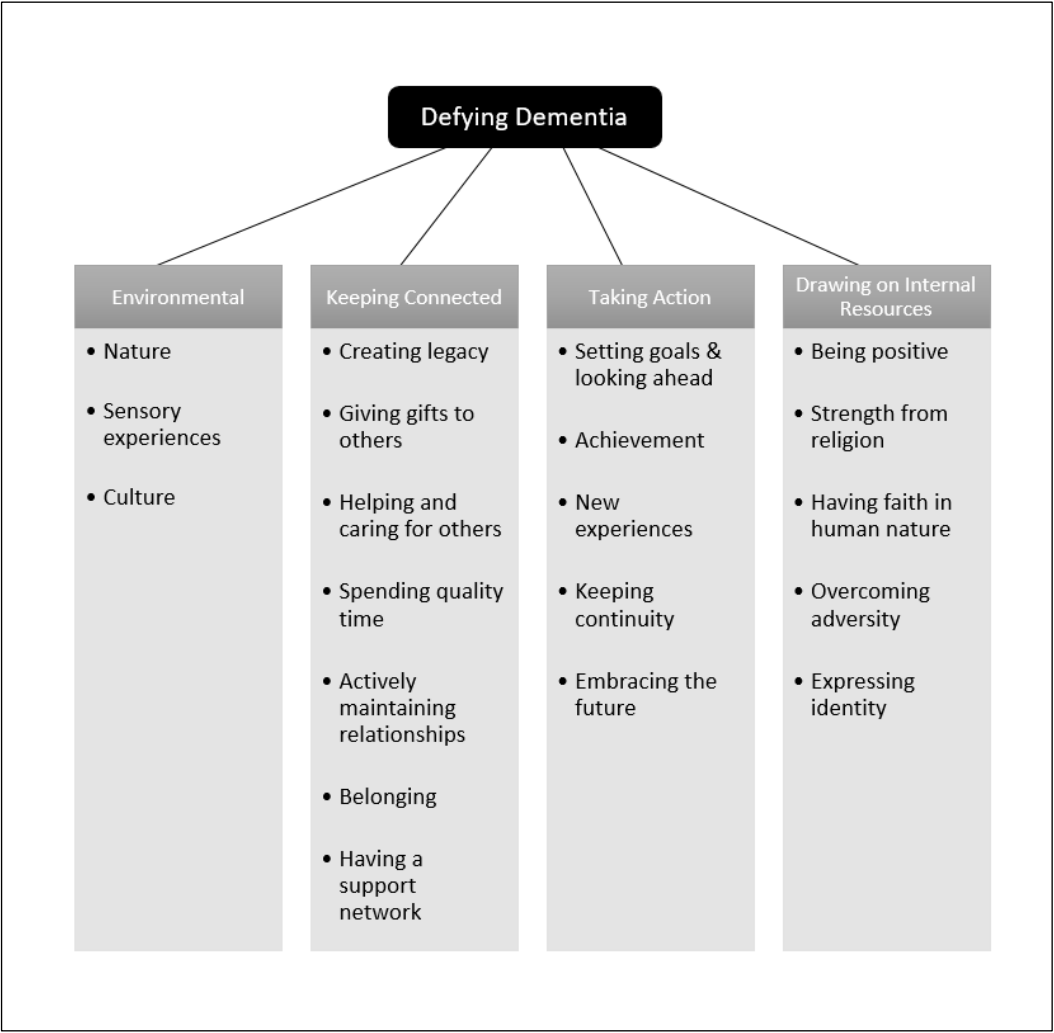


Figure 11 Where participant’s hope came from

4.5.1 Environmental Sources

**Nature**

All participants took photographs of nature and seemed to have a deep appreciation for their surroundings. Robert took pleasure in viewing his garden; *“yeah you know we’ve got different sort of plants and pots there...there’s um...polyanthus and ivy growing over the side of the...these are clay pots...lattice pots”* as well as watching the birds; *“yeah traffic control out there...you get all*

*these birds flying in and out*". Rachel took a photo of woodland she enjoyed walking in, one of a sunset, and also fields she saw from the window of the train. James took pictures of his allotment, and of the family walking in woodland with his grandchildren. Richard described the arresting nature of sunsets for him; *"(I) often just walk out of the front door and think crikey come and see this!"* and explained why he liked them; *"well they're so beautiful...in their own right"*. He enjoyed the view from his home which overlooked fields; *"looking out of the window is always an up"*, especially the horses who he liked to watch; *"it's rather fun"*. He also took pictures of baskets of flowers on display in built up areas, where nature, and his hopeful feelings were given a foothold. Robert loved the colour of trees; *"it's a nice autumn colour they've turned into so that's quite...quite quite nice"* as well as all the different varieties of plants and flowers he grew in his garden. Matthew admired the countryside in the area around where he lived, experiencing the seasons, and the beauty of the grounds of a stately home he and his family enjoyed walking in; *"we'll go and see it in different times of the year and all that stuff, and it's a stunning place, and when we go there don't we? we just say how fantastic it is"*. For him he did not always need to leave the house to feel the sense of hope nature could bring; *"no I do a lot of it now but it's just nice, having time in the garden"*. Ann took her camera on holiday to Scotland with her; *"there was nowhere in Scotland that you wouldn't have a lovely view"* and appreciated the proximity of the hotel to nature; *"it was just lovely because when you come out of the place we were staying in...the hotel...you can walk down and there's Loch Lomond...right in front of you...and it was just gorgeous"*. She took many pictures of flowers; in her back garden, and when visiting other places such as a botanical gardens where she is seen smiling surrounded by flowers; *"it's absolutely gorgeous!...it's really really lovely and...they have an indoor one"*. She said; *"I've always loved flowers"* and found it hard to choose her favourites; *"they are lovely...they're really really lovely...but then they're all lovely...full stop"*.

### **Sensory experiences**

Most participants focused on their describing that they could see, and perhaps due to her failing eyesight, Ann reported a range of different sensory experiences that brought hopeful feelings. Her sense of touch in particular was important to her for identifying her beloved plants, for handling tactile objects; *"well it could be anything that's lovely like stones and...you know...just things...for touching"*, appreciating the warmth of the sun on her face; *"you know you get it on your face and you just stop...you know...it's just really nice"* or of a heated greenhouse on holiday; *"it was nice and warm in there and we sat there for ages"*. She enjoyed the sensation of movement that the wave machine at a swimming pool created, and spoke of her love of music; *"I*

*love music...I have the radio on all the time...I do like classical...there's been great music on radio 2...there was Indian music...and it's just been brilliant...and I love that because it's just like listening to a new sort of style of music".* Matthew also enjoyed the sensation of the warm sunlight; *"you know...and this sounds...old but you know, when the sun's shining and you sit down with a cup of coffee outside...I couldn't tell you"* and this had effect on his mood; *"when you come out of the winter and um you know all of sudden you feel good...quite well because, you know, the sun's out".* Rachel meanwhile had a keen sense of smell and taste and spoke of her enjoyment of food, and eating out on a number of occasions, taking a photograph of a Sunday roast with Yorkshire puddings.

### **Culture**

For Richard hope sprung from his appreciation of culture, architecture and the arts and these featured heavily in his choice of pictures. He took multiple photographs of architectural structures such as historical buildings, bridges and cathedrals, and spoke of enjoying the experience of visiting cricket matches and cafes. One of his photograph was of a mural depicting the story of David and Goliath. He explained that he appreciated it as a piece of art but was also proud of himself for having been able to identify it on his own. Ann took pictures of an elaborately decorated fountain they found on holiday, a man playing the bagpipes, and spoke of enjoying experiencing things from other cultures such as Indian music. Rachel enjoyed the theatre meanwhile and took a photograph of a production of Robin Hood. Richard admired human achievement, and the engineers who built the bridges, trains and buildings he enjoyed looking at. Of a cathedral, he said; *"that's magnificent isn't it?...and it's not something I particularly like, but you have to admire the people who built it...and that's true of a lot of cathedrals".*

### **4.5.2. Keeping Connected**

#### ***Creating legacy***

Leaving a legacy through his teaching was important to Matthew and was an important source of hope. Of a photograph he took he said; *"so that's the school I used to work in...um...and that fits into the...you know...I feel like I've done something and left some...left something".* Bumping into ex-pupils and their families could recharge these hopeful feelings; *"he was just saying...oh...you were a good teacher and all that stuff...so that...that part of it was quite good"* and he was proud

of the part he had played in their success; *“you think I may not have done all of it but...I was sort of...and you know, there’s these people and you see them...you know...doing different things and you know, clever things sometimes...bloody hell!!!...I think having a...you know...having left something with someone...is probably a good thing”*. Matthew also found the idea of taking part in research hope-inducing as it could have the potential to benefit others as well as himself. Like Matthew, Rachel felt hopeful when she left a legacy, in her case through selling her mosaics. Matthew also derived hope and a sense of legacy from visiting a particular place with his family; *“I think it’s important for us...and you know...I’d like to think that...you know...in years to come that (wife’s name), or the kids or whatever...you know...that they think it’s somewhere they can...refer to”* and this brought a sense of permanence; *“and just knowing that’s...there...it’s one thing that’s going to be there for a long time”*. James’ life story book meanwhile provided hope for him, reminding him of his accomplishments in life and what he left behind; *“it’s good to look back...um...yeah I’ve got I’ve got a thing on the wall in the...in the other room which er my sister put together which is er...er...a review of my life”*.

### ***Giving gifts to others***

Both Rachel and Richard spoke about giving gifts to others and that this bolstered their hope. Richard was also proud of having helped his son to get on the property ladder, and Rachel described giving away possessions:

*“You know this lady...it it was a er...a garden swing...um it had been a bit misused and there was a little bit of green on it but came off with bleach...um and she just got a new baby...and she was just looking forward to giving it a spray paint and putting some cushions on it...so that she could sit outside with her baby? and stuff...and I’d rather give it away so it can be used...and...um...be appreciated rather than it being unappreciated just sat in my garden...and another project to do...that I’m never going to get round to doing”*. Rachel

She also gave away food when she had accidentally bought too much over Christmas, and explained why this made her more hopeful; *“so I just gave it all to him because that’s my solution, because that’s all it was doing was getting me down...because I didn’t want to go shopping again because I’d got all this food”*.

### ***Helping and caring for others***

Richard was also generous with his time, giving back; *“it’s a good thing to have done”*, while Ann enjoyed supporting others at the dementia café, help which was often reciprocated; *it’s really nice...that we go to the meetings, because you always...even can give some...some um help to somebody there...or...um...they...they could give us any...do you know what I mean?”*. Rachel enjoyed teaching other people with dementia how to make mosaics. Matthew wanted to help others through his teaching, and through research, and Robert remembered with pride having gone beyond the call of duty at work in order to benefit others. Another important part of Robert’s life was his cat who he enjoyed caring for and playing with; *“you know he has his breakfast in the morning...and then take his lunch, lunchtime and...change his water and that...(laughs) yeah...yeah...but he he’s a you know a sort of...he he comes running out and that sort of thing, and he always comes running along and he goes and he goes blleuuu!!”*. In the same way he takes tender care of his garden, and in particular his tree fern which he protects from the elements and refers to as ‘he’; *“right...he’s at the back of the shed now...wrapped up in polythene”*. Ann also takes care of her dog who she takes several pictures of joking; *“I love him...apparently I love him more than (her husband)!”* and Richard talks about his own dogs; *“they are a big part of our life”*. His own happiness and level of hope are also dependent on his wife’s; *“well if (wife’s name)’s happy then I’m happy”* which is relevant to any attempt at hope enhancing work.

### ***Spending quality time***

Spending ‘quality time’ with his wife brought Matthew hope:

*“The other thing is, I suppose we feel, I think, both of us...we spend more time together, as a pair, you know, because you’ll be rushing around, kids and that um...but it’s been really quite nice hasn’t it? The time, you know (affects an American accent) **quality time**...but it is quality time you know? and a couple of times we’ve said to the kids...do you know what? we’re going away now...yeah...and that’s...that’s been really really good...hasn’t it?”*. Matthew

Because he was no longer at work, he made the most of the time he had and said that he valued; *“having time to spend time with my wife and daughters and watching my teenage girls making decisions about the next stage of their lives and education”*. He valued the time to see friends; *“so we’ve started seeing friends who we haven’t seen for a...while...you know we’ve all got friends like*

*that you know? ...we must meet up and stuff like that, you know"... "it's been really nice, so we were in um...peak district last weekend...um and then a couple of weeks before that we went to stay with some friends in Guernsey... doing things like that and I'm going to go skiing with um...with some friends"* One of Ann's photographs was a picture of large family get together, and another of *"very good friends"* James treasured the time he got to spend with his grand-children as did Richard with his friends; *"I always look forward to speaking to him or seeing him, it's great"*. Hope therefore stemmed from, and also perhaps contributed towards people spending quality time with family and friends

### ***Actively maintaining relationships***

Participants were typically active in maintaining their relationships with others, Rachel looked for opportunities, asking a friend if she could join her next time there was an art exhibition, reaching out to others through her Facebook groups, and organising a trip to London to see her daughter. She regularly attended groups for people with dementia, as did Ann, who always tried to engage people in conversation who came to the house; *"well I always make an effort...I can have a conversation with them...you know....just (a) little short conversation...and that makes me feel good"*. Robert also made a point of ringing his (ex)boss in order to keep in touch; *"I worked there for...a good many years...yeah...um...and I...hadn't spoken to him for a while...and anyway...I...I...got in touch with him...yesterday I think it was...yeah um...and so I had a nice chat to him"*. Participants far from being passive and withdrawn reached out and did not allow their dementia to diminish their relationships with others.

### ***Belonging***

For Richard the place he went to University was important to him and he visited it regularly; *"it's like another family"* and he described going there as *"one of the best things I've ever done...it's lovely...it's a sort of coming home...they make us feel really good don't they?"*. For him the connection with his grandfather who also studied there made it extra special. Matthew also felt part of something bigger when he joined his local cycle club, which he said brought *"immense pleasure and friendship"*. Being part of a walking group also made James hopeful; *"we can have a chat with them and um er a beer and that's quite nice yeah because er we go down the pub...that's the last stop for us...before we er...go"*. Rachel's friends and family were scattered across the world, and she hoped that they would stay in touch; *"it's when I get a Skype or*

*something like that again...you know I'm hopeful that those friends even though they're not here can still remember to just occasionally give me a Skype or a phone or or something like that".* This sense of belonging therefore brought participants hope and seemed to meet a basic emotional need.

### ***Having a support network***

All participants described the importance of others to their wellbeing. Robert said that his wife made him hopeful, and when asked how he said; *"oh...she looks after me and...you know...just really happy"*. James said; *I've almost got a sort of a sort of a chain network of people...um my sister for example...um every now and again she'll phone phone up and say do you want to go to football?"*. Matthew spoke of his network, and saw it as essential to his hope; *"I've got strong family behind me and...friends and I...God I sit there and I think...how do these poor people...you know...manage...when they haven't got a family, and stuff like that Jesus"*. Ann's children lived nearby which was important to her; *"everybody's together...we're so near we can...literally...walk down there if we had to"*, but just having their photographs around the house was comforting to her; *"as long as I can see the children in the pictures...I'm alright...it's really nice"*. Her husband helped her to clothes shop which she greatly appreciated, and she said that the staff were always helpful. Rachel's support worker enabled her hope; *"so...I'm always hopeful every week that I've got somebody that will come and that we sort of...we're always laughing"* while Ann's support worker made her hopeful by taking her to visit leafy places, and she was glad of their shared interests. Her young granddaughter was also helpful, making her drinks and cakes; *"she's like a little carer...you don't even need to say anything to her"*.

The dementia café and meeting her peers was another important part of Ann's support network. She felt able to chat to the other people with dementia; *"It's easy to go and sit there, and talk to them because...we're all the same...more or less!"* and valued the support she was able to both give and receive; *"it's really nice that we go to the meetings, because you always...even can give some help to somebody there...or um...they could give us any...do you know what I mean?...so it's quite nice having all those people that I know"*. Like Matthew she couldn't imagine life without her support network; *"I mean...I can't believe if you had this thing (dementia) and...like it was just me and (husband's name) how you would...how it would work"*. Robert also enjoyed meeting other younger people with dementia; *"it was like a a gathering of various people with dementia and that...and you go there and have a coffee and that...so we do that every we go once a month...and we meet up with...yeah, it's quite a mixture really...various different Alzheimer's"*



*things isn't it? I would have thought". He agrees with his wife when she said that they were surprised about the amount of laughter there, having expected people to be very depressed about their situation. Matthew valued support from a local dementia charity, particularly the signposting and chance to connect with people around the time that he was diagnosed, although he found meeting other people with dementia unnerving at times as he felt that he was looking into the future. His cycle club also brought considerable hope and strength to him' "the friends made are now hugely appreciated and they really look out for me".*

#### 4.5.3. Taking Action

##### ***Setting goals and looking ahead***

Matthew spoke of the importance to him looking forward (as mentioned earlier) and of having goals; *"having...targets...that I can focus on"* and his hope was increased by thinking about a cycling trip he had planned in the French Alps with friends, saying it was; *"exciting and motivating to have this to look forward to"*. James also liked to know that he had things in front of him; *"yeah that helps I think, yeah ev-even if it's just a list of things we write down every now and again er you know it's going to happen"*. Ann looked forward to an upcoming holiday; *"well I'm looking forward immediately to going on the boat over to Ireland"*, and James to a holiday he and his wife were planning to Krakow. Robert looked forward to seeing his consultant at clinic appointments and also to an upcoming family gathering, and had chosen his outfit already even though it was not for another six weeks. Richard also looked forward to finishing a family history project; *"so...when I finish this book...when not if...when I finish it I shall present her with a copy of it and she will be...yes...and I'm really looking forward to that"*. James had plans for their allotment; *"the allotment is is going to be going to be the same shape generally...as it would be any other day...um 'cuz we're got it all marked off now 'cuz going to be boxes and er...yes...very good"* and enjoyed the challenge of working on it; *"this is just a bit like that but it's um its it's a challenge it's um...you know...finishing something"* as well as providing some reassurance that he was able to contribute; *"I'll always be digging"*. Robert found that he could always find himself new goals:

*"You're out there and you go out...what you intend to go out for five minutes I suppose but when you're there you find other things" and "I sort of look at something and I think oh well that's not quite right there...can sort of improve that and...you know...um...as I say yesterday I...where the back of the shed is and the back wall, is ivy that wants trimming down a bit you see"*. Robert

With pride and a sense of satisfaction he described a number of projects that he had completed. From a washing line system; *“so where the socket is to put the rotary line in...we can move the line, so it gets the sun”*, to reshaping a border; *“that curves around quite nicely”*, renovating the shed and putting in a new gravelled area; *“got batons of wood all the way along there...and there was another piece of wood underneath there which was the original, holding that back...um...so...we just screwed in through those and put all the slate along there”*. Other projects were ongoing; *“by the conservatory there was...there was a flower pot...ok? And...it had bulbs...you know I put some compost in then...put the bulbs in the bottom...then compost over the top...then build them up...lay them...and...it was there...and where the pot is...there is about that much...you know...to fill up and I (tuts)...when I go outside yesterday and get some more compost, and changed it, and put it in a different pot”*.

### **Achievement**

Richard took a number of photographs of his climb up to a castle on top of a steep hill on holiday; *“I was absolutely determined...I was not going to be beaten by it”*. When asked whether there was something about achievement that made him feel hopeful he replied *“oh big time”*. He clarified that it was not so much the winning as the challenging himself that was important. He also enjoyed watching sports such as cricket with a friend; *“it was very successful and that’s a really nice picture of him”* and rugby on television; *“I hope we go to bed on a high tonight,” ... “I look forward to this rugby match this evening in the hope that er...that my side would win”* and *“I will be glued to the rugby this afternoon”*. The frequency that James won table tennis didn’t matter to him; *“it’s not...wonderful table tennis but um...yeah every now and again I um win something”*. For him it was the hope that with the right mindset he could win every now and again, exceeding his own expectations; *“sometimes I get to a point where I say er...I can beat these guys...and I do...and it surprises me”* and *“yeah I think what I...I know sometimes that I...I can achieve to a level...um and then all of a sudden every now and again, I can do even better and that...and that makes me feel, well I suppose that you feel a bit euphoric”*. As has been mentioned previously, two participants, Rachel and Robert coached themselves to improve on their score on the MMSE, and James liked to push himself; *“because yeah my diagnosis is a challenge...um and it’s like sport... yeah just...I’m not...I’m not a very good loser...!”*. Ann even thought about doing a wing-walk for charity. Rachel’s achievements often came through creativity. She proudly took a photograph of a snowman she had made; *“that is actually a snowman Buddha”*...and also picture of a mural she had helped to create.

### ***New experiences***

Many participants enjoyed doing things they had never done before, Rachel for example enjoyed trying new types of art. Ann enjoyed listening to new types of music, seeing friends; *“because they come up with the weirdest things”*, and seeing unusual and new exhibits in the museum; *“it’s got the most weird things in there...it’s not stuffy...you’d think it would be...because there’s an awful lot of stuff that’s dead in there!”*. Richard was also excited by the unexpected, taking a picture of the crowd sitting on the cricket pitch during a lunch interval, and another of a statue he found unexpectedly down an alleyway on holiday; *“such an unlikely thing to find there! But there it is!”* and Robert recalled with delight the time a helicopter landed on the grass he tended, and the celebrities he had chatted to. Like the others Ann enjoyed broadening her horizons by visiting new places; *“the more you see of the world the better it is really,”* and for James going to Australia was a huge turning point in his regaining hope. Richard liked to be unpredictable and surprise his wife; *“I like doing things that (wife’s name) doesn’t know about because they give her some sort of surprise...hopefully good ones”* Like Robert, Richard also enjoyed meeting new and interesting people and visiting new churches; *“I like to see what people...do there...it’s interesting to see what the notices say for example”*. The new and unusual seemed particularly tied to hope therefore, with a reaching out and embracing of new experiences being important to participants.

### ***Keeping continuity***

While participants derived hope from new and different experiences, many also gained hope from continuity and routine. James said; *“um well when you think about it it’s probably repetitive situations and...(laughs) I said to (wife’s name) when we came back from holiday er after well twenty minutes I said well nothing’s changed and it hadn’t...really...the flowers are going to grow, the lawn needs re-mowing”*. Later he said; *“I have got an allotment so you can see...you can see flowers growing...so that...that’s er continuity”* and explained why this was important to him; *“flowers...are just sort of a repetitive thing, you know, it it’s good it has continuity that that um, I think it helps, particularly when you come out of the winter and um you know all of sudden you feel good...quite well because, you know, the sun’s out”*. The routine of getting ready to go walking was important to him as well; *“I think yeah I mean yeah yeah there’s certain things that we do that are regimented...um it’s just those little little details”*. Matthew similarly talked about how having a routine like doing the housework was helpful; *“it’s quite good because it sort of puts structure I think onto it and you think...oh...so I’ll do that...do that...and and...that makes it...just doing that when the garden was...you know...manageable...you know just doing things like that...I*

*found it quite enjoyable... don't tell anyone though!*". Robert had also begun to enjoy doing the housework when alone in the house during the day; *"I think oh right...right then...kitchen floor wants...washing...you see...quite a bit of the floor really so I get my kneeling pad out, and my bucket of water and I work round in a systemic...systematic order and...hoover and I hoover and things like that...I find something to do yeah"*. For him, being meticulous, and tidy was also important and he spent considerable time packing up all his gardening equipment even if out the next day he was going to get it all out again to do the same job. He also kept a diary; *"I write a diary every day...of what I've done...write a diary every day...(amused) well...I've got (laughs) two or three diaries actually"*.

### ***Embracing the future***

Robert prepared for the future to reduce the impact that his dementia would have on his wife, and this made him hopeful, which had links to leaving a legacy. He had created a low maintenance garden which his wife would be able to maintain by herself one day when he is no longer able. This preparation has given him a sense of control and had increased his hope rather than reduced it. Ann had also made plans; *"I'm not going anywhere!"* and she and her husband had arranged for the house to be converted; *"we've gone through the house...I just have to think about everything...it's...everything is made easier and so that's probably why...I'm...quite happy"*. Rachel similarly thought of her daughter:

*"I just, I tried to 'cuz of the dementia and 'cuz of the I don't know where anything's going to go and...yeah then um...I would rather...I don't want my daughter to be burdened...you know when anything happens...if you see what I'm saying? so I only want to keep beautiful things around me and things that have some significance?"* and she described how her views had changed; *"because you don't need huge amounts of stuff all of the things what I thought was important...a lot of those things are still in Spain... so I don't feel the n...I mean I used to be an interior designer so so everything was yeah top of the range...the latest thing...the newest inventions, the latest fabrics the this the that and high spec everything um...I don't feel the need to do any of that now, for myself or for other people."* Rachel

#### 4.5.4. Drawing on internal resources

##### ***Being positive***

Many participants were able to look to the positives and focus on these as well as their strengths rather than focusing on what they could no longer do. The way in which Rachel turned around a negative, the snow, and turned it into an opportunity to be creative showed great resilience. Richard similarly described the rain as being good for the grass, rather than expressing regret that it has spoiled his summer. All participants had a sense of fun and made jokes during the interviews. Fun has previously been considered as part of the qualities of hope (p87) as has humour (p93). Fun and humour appeared to be resources that participants drew on and which gave them strength. For Richard this was an essential part of coping with having dementia.

##### ***Strength from religion***

The hope inducing aspects of Richard's faith were the people; *"I like to see what people...do there...it's interesting to see what the notices say for example"*, and he enjoyed meeting other people in the congregation, being proud to have met a Baroness in church once. He spoke of having enjoyed taking his son-in-law to church with him, and for him the worship was almost secondary; *"there are people still...it's still (a) place where people go together to...maybe to worship but it doesn't have to be that at all...people will go to the church to do all kinds of things"*. Rachel was a very spiritual person who had beliefs which came from many different religions. For her crosses as a symbol had a hopeful quality that she couldn't quite explain; *"that's just some of my mosaics are just crosses they always make me feel really hopeful...for whatever reason...birthday...Christening...faith...mmm...death...everything"*.

##### ***Having faith in human nature***

When Rachel's faith in human nature was restored this brought her hope; *"yeah yeah that there are kind people out there and people that do care"*. Richard was overcome with the thoughtfulness of a friend who had surprised him by deliberately parking near his old school which he had fond memories of. He was also very taken with the idea of people looking after cathedrals and churches; *"the love that someone put into making these things and...the extent to which it's been looked after for goodness knows how long...hundreds...hundreds of years..."*.

## Chapter 4

Rachel also felt faith in human nature when she saw the restoration that was taking place after the hotel fire, and she took pictures of pigeons in a square because they made her hopeful for what many may consider a very unusual reason; *“it was just three pigeons sort of sat huddled on these stairs um and...er there had been a lady throwing out bread? so again it’s back to trying to take care of what we already have?”*. It did not matter to Rachel whether she personally liked the birds; *“even though pigeons in my opinion aren’t worth feeding um there’s somebody who does think that they’re worth feeding”* it was about her faith in human nature.

Rachel took photographs of flooding, which represented another slightly unexpected source of hope for her:

*“That’s all floods...well it’s just about the elements and different things you’ve got this lovely sort of blue sky and hedges and then all this water that’s all you know...sort of like come down from the heavens and sort of been held, thankfully these fields don’t have livestock...or anything like that um...but again I’m just hopeful that one day we’ll realise that we can’t really control the weather? And we’ll start to think about...you know...um what we do when we do have those things happening? like those poor people in Scotland”* Rachel

Rachel also took photographs of a city she visited; *“it was in Birmingham...I think it was just of the fact that sort of like new...being built next to old...and just how it’s all changed and you’ve got all these people there cleaning all these panels you know so...um...in in this sort sort of like modern structure and everything that you’ve got there’s still work for people you know to maintain it and...and you know keep it looking...(good)”*. Having faith in human nature was a strong source of hope for Rachel therefore, although she was the only person to report this. For Rachel, this was possibly linked to the notion of ‘keeping connected’ (section 8.2) and a belief that the world was a benevolent place, one which was worth reaching out to (as she lived alone).

### **Overcoming adversity**

Overcoming adversity had links to other themes already identified such as resilience (p82) and perseverance (p87). When Robert told the story of the hurricane just recalling it seemed to bring him hope and strength. He similarly described overcoming adversity while taking part in a two day research project involving prolonged time in an MRI scanner. He was proud to be the only person to have made it to the end, and attributed his success to his philosophy of *“mind over matter”*. Participants were all able to see that life continued despite dementia. Their hope was subject to

knock backs (e.g. darkness, fire damage, cold winters, bad weather) which they both expected and anticipated. These knockbacks did not destroy their hope however which was strengthened by the process, and they chose to see regeneration rather than destruction. It was unclear to what extent this was a conscious process, but Rachel in particular demonstrated considerable awareness and was able to articulate this well as will be seen (e.g. p123 & 129).

### ***Expressing identity***

Interestingly both Robert and Matthew referred to hope coming from activities which seemed to re-enforce their masculinity and gender role, with Robert taking multiple photographs of these subjects. Matthew said, slightly conspiratorially of cutting the grass; *"yes...(whispered) because it's my thing! it's boys...it's what boys do!!"* and Robert spoke at length about his 'man shed' where he kept all of his tools. Ann meanwhile took on a slightly different role, enjoying being with her grandchildren who saw past her dementia; *"it doesn't matter what you've got you know...a Granny is a Granny isn't she?"*.

### **4.5.5. Visual Model**

As has been discussed, hope came from four main sources, and these often overlapped and interacted with one another. The very visual nature of the task, and of the metaphors used seemed to lend itself to a visual model of some kind explaining this relationship. Inspired by Ann and Robert's love of their gardens, the importance of the outside world to all participants, and the description by Deegan (1996) of hope as a seedling requiring the correct environment to grow, a visual model of an eco-system surrounding hope was created (see figure 12 on the following page). Hope sprung from the surrounding environment, represented by the sun, which itself represents hopeful places such as gardens, and an immersion in culture and achievement. The person's internal resources (their resilience) are symbolised by the deep roots of the seedling, keeping the plant tethered), and 'keeping connected' to others by the soil that binds the roots (others who provide strength and nurturing). Meanwhile 'taking action' (adding water, or acting to keep healthy) is an important ingredient in growing hope and which requires effort by the individual. Hope therefore can be seen to stem from both active and passive processes and from oneself, and from others. Rather than representing a contradiction this can be seen as a

harmonious interrelated ecosystem. In the next section this idea will be built on by examining the barriers to hope.

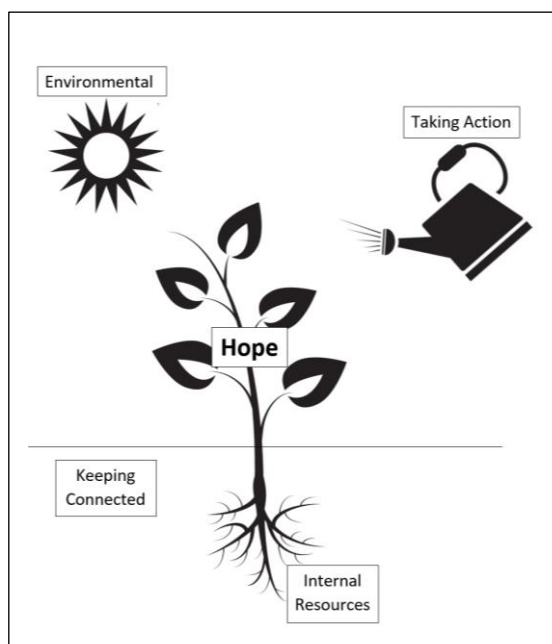


Figure 12 A visual representation of what allows hope to flourish

## 4.6 Barriers to hope

All participants could identify what made them less hopeful. The following in vivo codes were generated; fear of dementia, threats to identity, disconnection from others, and frustrations and restrictions (see figure 13 on the following page, and also appendix J). One participant, James, had used the phrase “*cast adrift*” to summarise his feelings about losing hope when memory services discharged him. Robert’s wife used a similar phrase “*being left to flounder*” and this seemed a useful way of summing up participant’s experiences.



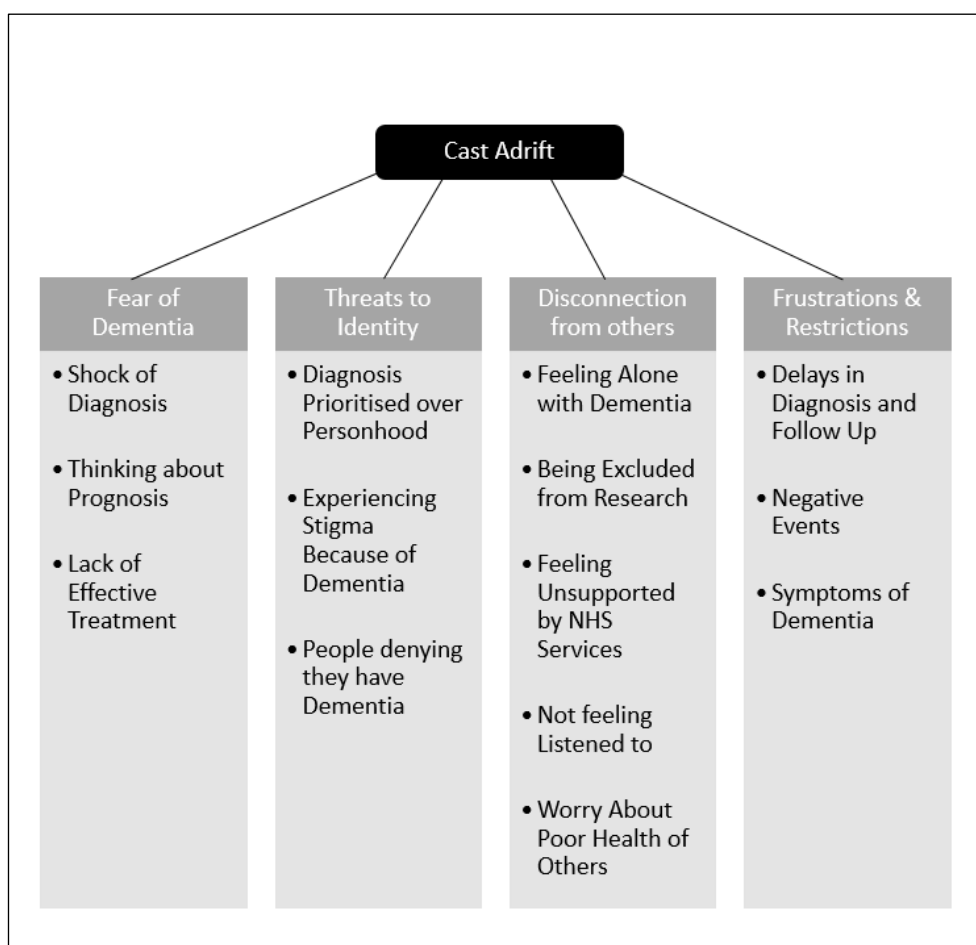


Figure 13 Themes regarding barriers to hope, and causes of hopelessness

#### 4.6.1. Fear of Dementia

##### *Shock of diagnosis*

James was shocked when he received his diagnosis as it was not what he had been expecting; *“when I first had the diagnosis, it’s just sort of er it felt like it was sort of almost the end of the world... yeah we just didn’t know what to think did we? And we didn’t know who to ask...(pause) yeah! Yeah it w-w-was a bolt out of the blue”*. He referred to that period as ‘dark days’; *“when it started, um I mean t-t-t-t-hey seem um sort of quite dark days...um that have gone you know because er um er when I first had the problem um we didn’t know whether to whether to laugh or cry”*. He and his wife didn’t take up the offers of support, saying; *“we were probably frightened at the time”*.

Matthew felt similarly traumatised; *“it is sort of a bit of a blur...that that period... and I know I wasn’t thinking particularly straight or anything like that”*. Mathew had been diagnosed the most recently of all the participants and perhaps this was partly why shock was still quite evident; *“we...weren’t expecting it. I re...I just sort of thought well they’re bound to say that they can’t see anything on the...on the scan”* as well as grief; *“when you see the young people and all that stuff, and you see the parents. I mean last night in Sainsbury’s this woman was crying her eyes out, and I’m sort of standing there thinking...yeeeaaaassss”* and the anger; *“so that whole thing was just shit”*. The way in which Matthew’s diagnosis was broken to him was a key factor in his loss of hope, and he expressed anger:

*“We were just in a ward...we were just in a ward! You know, it wasn’t even in a private room or anything...”and it was just poor!!! I don’t know what you do but...I mean...no I just think actually you know, when you give somebody...you know...life changing news I just think there’s probably lots of very good practice about how to do it and...and that wasn’t what happened really”*. Matthew

### **Thinking about prognosis**

Mathew put on a brave face, but the future for him was frightening; *“that is difficult because you look...you can’t help but looking at people and think...(with sadness) that’s going to be me...”*. He recounted a walk where he had met other people with dementia; “

*I came back...quite shocked by that didn’t I? and quite...and um...(laughs) oh yeah, and then we came back to the pub, a couple, you know chugging it away at lunchtime!! and it wasn’t even lunchtime actually...and I thought, oh my God, because you sit there, you know and you think...is that going to be me?”*. Thinking about his prognosis was at times very painful and a major barrier to Matthew’s hope; *“if you’re not in a a great mood you can just (makes pretend weeping noises) um...but...I guess that’s only been a couple of times I guess hasn’t it when I’ve had a bit of a breakdown...but...er...yeah...once or twice...but not a lot and you know you just think (makes pretend weeping noises)*. Richard found that his prognosis could threaten his hopeful outlook; *“I was only told what was going to happen and...I can cope with some of it”*, but Robert spoke little of his illness and it was unclear whether this really affected his hope or not.

### ***Lack of effective treatment***

Lack of a cure or effective treatment was an issue for Richard; *“the best thing they could do was get a group of other people with the same thing...it didn’t help much really”*. Matthew’s hope was initially bolstered by the thought of taking cognitive enhancing medication, but his expectations of its efficacy changed over time and this affected his hope; *“when we first...when we first went they said “oh yeah yeah yeah yeah...you know you can try some of this, when it’s all sorted” and I thought that’s great, and when we came back and saw them again they said well you know it’s not really...they didn’t...they played it down massiv...quite a lot compared with the way they’ve done it before”*. Feeling mistrusting, he then even wondered whether the artificial manipulation of his hope was what the real purpose was; *“I sometimes think...is this just...you know...to keep me busy you know...and feel like something’s happening?... what’s it called when you do something...arghhh!!! ...placebo and I was thinking I mean...are they doing this on them...you know...just to keep me a bit hap...”* but he also had doubt *“I don’t know...I might be a bit of a cynical old bugger...but um...I sometimes think that”*.

Matthew’s wife explained their frustration that nothing medically could be done; *“for a lot of things of course...they then can say well yes we can chop this bit off or we can operate, or we can take that bit out and we can pile you in with these drugs...and effectively...sadly...for Alzheimer’s they don’t have any of that...and it is all too apparent that, you know we’ll see you in 6 months, we’ll test you again and see where you are”*. Matthew recalled the conversation they had with his consultant; *“and you said...what was that comment you made to them?”* to which his wife replied slightly sheepishly; *“God...! you’re just going to measure the decline what’s the point of us coming”* and he appeared to share the sense of futility of future appointments; *“I was just sort of like...well what...you know...what is...what is the point...?”*.

#### **4.6.2. Threats to Identity**

##### ***Diagnosis prioritised over personhood***

Matthew was clearly still traumatised by how his diagnosis was given, and that his personhood was denied to him. He explained what happened when he arrived at the hospital for his head scan results, and said that he was met by two junior doctors; *“they said right...(claps hands) we’re here for your...(lumbar puncture) and I said no! no no no no!!! we’re here to look at the...no!! and it was like, and then these two people start having an argument with each other...about what should be going on, and I’m thinking...oh...This is not very good at all...because you don’t want to see people*

*arguing do you really?”*. The confusion caused him some distress; *“so that was a big shock for both of us...’cause you’re going in expecting one thing...and you get another...and humans don’t like...not knowing what is happening and why”* and this affected his confidence in the service; *“and you know...looking outside well you know you think...well the process can’t be that difficult...”*. He said that he agreed to the lumbar puncture on the basis that he wanted to avoid further delays, but there was also power imbalance between himself and the professionals.

The lumbar puncture despite being painful didn’t affect his hope, in fact he said that he was proud of how brave he was; *“I thought I was quite tough for me actually”*. What affected his hope was the way in which his personhood was ignored afterwards. He said that a doctor had told him to lay flat at all costs for a set period of time following the procedure, in order to avoid a severe headache but another doctor then asked him to get up off the bed as he needed to perform some tests that had been forgotten earlier, and asked him to walk around the room. Matthew complied, but he felt that he was being treated like an object rather than a person, with diagnostics taking priority over his well-being. When he was given his diagnosis of Alzheimer’s Disease he was laying flat in bed; *“yes that’s right...I was still laying there from... (the lumbar puncture)”* which he found undignified and uncomfortable, and he could not contribute to the conversation. He was also uncomfortable about the lack of privacy as this conversation took place on an open ward, and he was surrounded by a large group of professionals who he did not know (most he said were there for their own learning). He said that his mind was reeling and he struggled to take the information in or think what he needed to ask: *“he said (speaks fast) ‘oh have you any questions now?’ do you remember? And it was like arghh!! because your brain is...you...you know!”*. A voice-centred method clearly shows that the needs of the institution (timely diagnostics, education, prestige) were prioritised over Matthew’s own needs (psychological support, education, privacy, dignity, choice) and that this had led to his subsequent loss of hope.

### ***Experiencing stigma because of dementia***

Rachel and Robert mentioned that people could be impatient with them because of their cognitive difficulties. Robert’s aunt was kindly in many ways but he said she; *“still shouts at me and says; you told me that...you told me that last time!”* even though she was aware of his illness and how it affected him. Rachel mentioned that her dementia symptoms could cause her problems in shops; *“we do all get these altercations or whatever they’re called um...er...er...at the...er checkout...yeah because you know we’re being slow, or we’ve forgotten how to count our*

*money...or...you know...not getting our money out quick enough or just stuff like that*". This had less impact on her hope than it used to and she felt able to assert herself more than she used to; *"I'm I just...nowadays I'm just too long in the tooth...to to be bothering...and I just say...look...I might not look like it but I have dementia...please be patient"*. In this way Rachel was open about her condition using this to help her struggle against the abuse she experienced showing signs of 'political resistance' (Brown & Gilligan, 1993). James said that he had not experienced stigma first hand and felt that overt rudeness by others to his face was unlikely but he still felt that dementia might have stigma attached to it *"no people probably wouldn't do it, but...um yeah but I'm sure I'm sure there's still a stigma."* Like Rachel he hinted that he would resist this stigmatisation if it occurred; *"...I mean I mean I can fight my corner um but..."* but when his wife said that she did not believe stigma still existed he began to capitulate and self-silence; *"it um no I j-j-j-just think sometimes people...or perhaps it's just me...er...thinking wrongly"*, showing 'psychological resistance' (Brown & Gilligan, 1993).

No-one reported stigma as overt as Ann however, and for her this came from her own family. She felt that her mother's attitude had changed towards her since her dementia diagnosis; *"well she's ashamed"*, although she admitted that to some extent they had always had a difficult relationship. She was deeply affected by her mother's lack of concern when she told her about her illness, especially as she had tried to protect her mother's feelings:

*"Well when I told her eventually...because we didn't tell her for 3 years, the girls knew for 3 years...I just didn't know how to say it...cuz it's like...oh I wouldn't...like to hurt her...you know....? and then...when we decided...well...they'll probably be over the centre, and they might see people and they might say "oh and wasn't it a shame about your [Ann]? And blah de blah de blah" d'you what I mean? so we did go there there...and I said to her what I've got...and [husband's name] can tell you...what she said..."*. Ann

Her husband then explained that she had said *"well who's going to look after us now?"* and she explained how this continues to deeply affect her; *"I don't think...I don't think...even if I lose my...mind...I don't think I'll forget that"*. Ann said that her mother had then asked; *"well who have you told?"* which she took to reflect her mother's fear of what others would think. Ann fought against her mother's stigmatisation of her, but not without experiencing guilt; *"it sounds a bit hard...but if you had my mother"*. Her strategy of avoiding her mother did not always go smoothly however as her husband sometimes tried to talk her into going; *"the other day...we come home and (her husband) said 'oh let's just pop in...just...pop in..."* and she showed evidence of resistance to this; *"...and I went MENTAL didn't I? I said NO! didn't I?...I went MENTAL."*

Bravely, Ann also described her own preconceived ideas about dementia which had appeared to initially present a barrier to her attending a local support group and to her hope; *“the first time I went I said to [husband’s name]...I said I don’t really want to go, I said I don’t want to go somewhere where there’s people just dribbling and doing...and you know...do you know what I mean? because you don’t know any different”* but she was pleased that she went and enjoyed herself; *“and um...it was...it was really really good. Yeah”*, becoming a regular attender.

### ***Other people denying that they have dementia***

Ann said that her parents caused her to lose hope when they denied the presence of her dementia; *“they don’t think that I’ve really got anything wrong with me”*. The voice-centred relational method revealed that this invalidated her experience and the struggles that she experienced due to her dementia. Rachel also found that people did not always believe that she had dementia, and that they could respond negatively, even aggressively when she told them; *“sometimes you get a throwback like ‘don’t talk shit’”*. Robert also found that he was not always believed and that his experience could be denied, albeit in a more polite way; *“the one chap who comes at um...yeah...’cause (laughs) ‘cause he always says ‘nah you haven’t got Alzheimer’s’ and that and I’m like ‘yes I have!’”*. All three expressed strong negative emotions associated with this.

### **4.6.3. Disconnection from others**

#### ***Being alone with dementia***

Matthew’s story about his diagnosis was powerful, and it was clear that he and his wife felt very alone at this point; *“and at the end...at the end of the thing he said...”oh I’m really sorry” and they said “you’ll probably want some time together”, and er...he walked off...and there’s (wife’s name) and I having a...having a...a bit of a blub...then it’s like...oh what do I do now? There’s no-one around!! And we’re like in this half empty place and it’s just like...so I said...oh we’ll go now then, and it’s just like...there wasn’t anyone there to support us”*. When asked what he would like to have happened instead, he revealed the true extent of the hopelessness he felt at that time; *“I wouldn’t have that situation whereby you go off on your own...I might have topped myself as a result of that”*. Matthew felt alone with his dementia and hopeless when he went to meet other younger people with dementia and found himself being the youngest; *“we haven’t met very many*

*people...who are sort of...my age...people say 'oh there's lots and lots of people...lots of people your age' and I thought...(disappointed) just show me one...just show me one...and we haven't seen one have we?"*

### ***Being excluded from research***

Matthew had put his faith in drug trials to help slow his illness, but his hopes were dashed when his scores on the cognitive testing proved to be too low for him to take part, his disappointment palpable; *"and um...and you think...hold on...here I am...you know? I'm fairly fit and da-de-da-de-da-de-da...and it looks like...that...um, you know, I won't be required for that which is a real...it's really, you know...it's like sort of being...yeah rejected by the whole thing...and I can understand why you'd want to do it and...and um so that's been...a little bit of a knock back hasn't it?"*

### ***Feeling unsupported by NHS services***

James felt abandoned by NHS services and *"cast adrift"* when he was discharged, as has previously been mentioned. Matthew felt that he didn't have enough time when seen by his consultant; *"it was all very...so rushed actually...you need a bit of time..."* and felt that his consultant's focus was on getting somewhere else; *"he'd been doing his clinic for hours and hours and hours, I don't know it was about 1 or 2 in the afternoon and he had to be somewhere else so..."*. He felt that he needed more time to take the information in and worried that this might be even more of an issue for older people: *"but when you get that little old people are being told this as well...they're not necessarily gonna know, they're going to go home and think...what was that again?"*. Rachel was happier with the NHS dementia services she received than she was with the services in Spain, but she did feel unsupported at times such as when people overestimated her abilities; *"in Spain they finalised my...mmm...dementia by doing some kind of...I think they called it a SPECT...um...and it comes up in all different colours and things like that and they were going... 'oh you had a SPECT well where is it?' and I'm like well it's in Spain and they were like 'well you have to get it' and I'm like well...I don't know how to do that"*.

### ***Not feeling listened to***

Rachel did not always feel that she was being fully listened to and this could make her feel hopeless. She recounted an appointment with a psychiatrist:

*“One of the first things she said I’ll take you off...because I take Aricept? and she said “no you don’t even need you don’t even need that” and...it my daughter [name redacted] and me...and we all screamed at the same time “oh yes she does!” and like “yeah I do” because it was one of the tablets that was introduced on its own...that really started to...help...so for her first bit of advice to be... “no you don’t need it” I ‘aint gonna like her...do you know what I mean...I lost interest in her completely and just shut down...um...but I know I can shut down...and that is when somebody is putting me down...or really not listening”.*

### **Worry about the poor health of others**

When the health of other people with dementia declined and they stopped coming to the dementia cafe this also had an impact on Ann’s hope; *“I’m quite sad if somebody...isn’t there anymore”* and she showed concern for their welfare; *“I do worry about them”*. She also worried that her dementia would lead to increased dependency on others. Richard’s mother’s ill health following a stroke was a barrier to his hope meanwhile; *“it’s ghastly...her right side is completely hopeless”*.

#### **4.6.4. Frustrations and restrictions**

##### ***Delays in diagnosis and follow up***

Rachel was given her diagnosis of dementia when she was living in a different country and after a long period of uncertainty, hospitalisation and having first been given an entirely different diagnosis which eroded her hope. The uncertainty was hard for her as she knew that something was wrong, and when she was given a diagnosis of vascular dementia this came almost as a relief; *“I understand it more now because they say I have sub-cortical vascular dementia?”* and this reduced her level of frustration; *“I don’t get as frustrated as I used to...prior to the diagnosis”*. The



build up to Matthew's diagnosis; the wait to be seen by a specialist, and for the scan results was difficult for him; *"why can't I be seen now? ...they say we'll see you and it's just like a long time away...having to wait...that's...that's quite...it's very frustrating...when you want to know...what have I got? Have I got something? And they say yes and we'll discuss that in...you know...couple of months...no!!"*. The follow up also didn't happen as soon as he had expected either and this affected his hope too; *"when we went back to the consultant at the end of October for sort of the confirmation bit, really...appointment...yeah and he said...it is that...and um...basically we'll see you in six months, and it's just like...(jaw dropping impression)...is that it then? and that was a bit of a...and I understand, but it was a bit you know...give me a bit more than that...you know I've paid my money...I've done, you know...I'm not a bad person I don't think...and it (exhales) I sometimes...you know looked at that when we came away and I just thought...is that it?"*.

### **Negative events**

Many participants expressed a loss of hope unrelated to their dementia, suggesting that the ups and downs of everyday life had an impact on their hope and that they were still very much affected by the world around them. In Robert's case it was striking that he did not see his dementia as being a barrier to his hope but the loss of his favourite TV show was; *"they've taken away Bergerac...!!!*. Richard similarly expressed great sadness at the decline of the steel industry and of steam trains, both interests of his since he was a child; *"that has just been wiped out...not only the trains...practically everything in Port Talbot has gone"*. His hope could be dampened, but just not currently by his dementia. Geography also separated him from close friends who he enjoyed seeing, and he spoke about the importance of good weather; *"I think it's very important on holiday...particularly on a boat...you really don't want rain"*. Ann found that listening to the news on television or listening to it on the radio could have an effect on her level of hope; *"it's miserable isn't it?"* but felt it her duty to keep up to date with what was happening in the world none the less; *"but no you've got to...keep abreast of everything...so"*. Ann's efforts to stay connected to the world could have a negative effect on her hope therefore.

### **Symptoms of dementia**

For Ann her dementia restricted her independence at times; *"when I've got a rubbish head I'll not go anywhere"* and *"I don't go anywhere on my own"*, and how her husband had needed to take over many of the gardening tasks; *"I used to make them from seeds...well I sort of do now but*

*he...he...does the grass now don't you?"*. Yet despite this Ann never spoke fearfully of her illness or the future, nor seemed to point to it directly affecting her hope. Rachel spoke articulately about the difficulties that her dementia created. A trip to London on the train for example took a long time for her to organise herself, yet was also a huge source of hope and satisfaction for her when she accomplished it. Sometimes she did lack confidence however; *"I usually...I like to go with somebody because I've lost the confidence to just go out and head off into the woods on my own um...I don't know what the fear is but I just don't feel as comfortable yeah...so...I don't do as much of it as I like"*. She had difficulty reading, and this could derail her plans sometimes particularly in busy environments like restaurants but she still tried to be as independent as possible. Richard also had difficulty with language, but because what was most important to him he could still do, his hope was not particularly affected; *"I have real trouble with complex...words and stories...but sort of...playing around...joking and so on that's still intact...thank God...if I didn't have that I'd be pretty grim"*. James similarly had symptoms which he found frustrating, but he kept going and did not lose hope; *"I think sometimes...sometimes I just get so frustrated er with it but it doesn't you know, it doesn't really stop me from doing things but but um...I I (exhales) I've just got used to it I suppose"*. He hinted that if his symptoms worsened this might not necessarily continue to be the case however; *"if I can't...you know if I can't achieve I suppose that could that could be a problem er if I suddenly got worse for example"*.

### 4.6.5. Summary

Being cast adrift, or losing hope, could result from disconnection from others, and from frustrations and restrictions placed upon the person such as delays in diagnosis and follow up. Within the ecosystem model this might be visualised as the seedling becoming loose and untethered to the ground, and from restrictions such as objects or other plants restricting access to light or other resources. The following discussion section will seek to understand these results better, what these mean for other people with dementia, and for the work of mental health professionals working with them .

## **Chapter 5: Discussion**

### **5.1 Research Aims and Objectives**

To date little has been explicitly written about the hope of people with dementia, particularly younger people. This thesis set out to address this gap by exploring how younger people living at home perceive hope, and how their perceptions might inform and improve community nursing practice. It sought to understand barriers to hope as people with dementia report them themselves and what might enhance their hope. The objectives of the research were to establish the significance of perceptions of hope to younger people with dementia, to understand where people feel their hope comes from and what allows it to flourish, and to identify the barriers to people with dementia feeling hopeful. These shall now be discussed in turn.

### **5.2 Perceptions of Hope to People with Dementia**

Hope was important to younger people with dementia in this study, and participants saw themselves as having a future. This was in line with previous studies (Aminzadeh et al, 2007; Beucher & Grando, 2009; Dalby et al, 2011; O'Sullivan et al, 2014; Pipon-Young et al, 2012) As found by Clare et al (2008a) and MacRae (2008), hope seemed to be sustaining, realistic (Radbourne, 2008) and seemed to help participants to live in the present as well as living with the future (Radbourne, 2008; Wolverson et al, 2010). Four overarching themes had been identified in the literature in terms of what people with dementia hope for; deliverance, helping others, maintaining abilities including insight, and continuing to live and enjoying life (see figure 14 on the following page).

What people with dementia hope for	
Themes from the literature	Themes from this study
Deliverance	N/A
Helping others	Contact with others
Maintaining abilities including insight	Good health
Continuing to live and enjoying life	Enjoyable events
	Success in endeavours
	A better world

Figure 14 comparison of themes from the literature and this study regarding what people with dementia hope for

Participants in this study did not generally hope for deliverance from their dementia, and this represented a major departure from some previous studies. None hoped for example that they had been misdiagnosed (Clare, 2002; Weezak & Stewart, 2002), that they would be cured (Lindstrom et al, 2006; Phinney, 2008; Radbourne, 2008) or that they would die before their illness progressed (De Witt et al, 2010). Robert hoped that one day a cure might be found, but that it would help others rather than himself. One participant (Richard) spoke about his belief in the afterlife, but he did not speak of it with the same sense of longing and expectation of release that others have previously reported (Davis, 1989; Stuckey, 2003; Snyder, 2003; Dalby et al, 2011). This implies that hope is not tied to cure or the absence of symptoms for people with dementia and that a broader understanding of hope is possible.

Like Davis (1989) and Henderson (1998), participants expressed a desire to help others. They also had hope that they may be able to maintain their abilities for as long as possible, with deterioration of their illness being slow, a common finding elsewhere (Lindstrom et al, 2006; Phinney et al, 2007; Radbourne, 2008; MacRae, 2008; Genoe, 2009; MacRae, 2010; Genoe & Dupuis, 2014). Continuing to live and enjoy life was a major theme from the literature also seen in this study, particularly being busy and active (Phinney et al, 2007; Phinney et al, 2008; Radbourne, 2008; Genoe, 2009).

Although most participants were taking cognitive enhancing medications, they had little hope invested in these and openly doubted their efficacy, unlike in Lindstrom et al (2006) and Clare

(2002) where great enthusiasm was shown. Matthew even wondered if his medication was a placebo. There was similarly only lukewarm feeling about biomedical research, unlike Phinney (2008), Genoe (2009) and Genoe & Dupuis (2014), this being mentioned by only one person in this study. This supports the idea that again hope is not tied to cure in people with dementia.

None of the participants minimised their illness, nor did they appear to be in denial unlike participants in Bahro et al (1995) and Harvath's (2010) studies. In fact the voice-centred relational method revealed that it was other people who denied their dementia, with participants feeling that this was because they didn't look typical of people with the illness. Participants sometimes appeared proud of this and of not conforming to societal views of how people with dementia should behave (most notably Ann and her wish to do a wing walk). None of the participants appeared to view hope as a negative phenomenon, for example being dysfunctional and maladaptive" (Bergin & Walsh, 2005) or saw despair as an ally (O'Hara, 2011). None expressed a wish for the 'work of despair' or for a lowering of expectations about what they could achieve; 'surviving not thriving' (Bergin & Walsh, 2005). Instead participants in this study were proof of thriving being possible in dementia and they embraced rather than avoided their future. None of the participants spoke of hope being a burden, or of hiding their despair. It should be noted however that the presence of their partners in the interviews may have made this more difficult for them to convey.

### **5.3 Where People Feel Their Hope Comes from and what Allows it to Flourish**

Participants saw hope as a fundamental part of wellbeing in line with mental health recovery approaches. Restoring meaning and purpose and 'living well with dementia' appeared to be important to participants, supporting the view of Woods (2007), Adams (2010), Hill et al (2010), Gavan (2011) and Pison-Young et al (2012) that the concept of recovery is relevant to people with dementia.

Hope could be affected by others, as suggested by critical approaches, and people in this study used positive coping strategies as described by nursing approaches, with evidence of both agency and pathway thinking described in cognitive and positive psychology.

Themes between this study and those seen in the literature were broadly similar (see figure 15 below) with a small number of differences. For example as mentioned in section 6.2 science was not a particularly important source of hope for younger people with dementia in this study, in

Where hope comes from	
Themes from the literature	Themes from this study
Science	N/A
Working for the greater good	Taking action  Drawing on internal resources
Practical coping	
Personal positivity	
Religion/spirituality	
Family	Keeping connected
Professionals	
Peers	
General/others	
N/A	Environmental

Figure 15 Comparison of themes from the literature and this study; where hope comes from

contrast to the rest of the literature. The surrounding environment and nature were also very strong sources of hope to participants in this study, but this was not seen elsewhere. This may be because there has not yet been sufficient research on this subject, because interesting other studies have shown that the outdoors is still important to people with dementia; serving as an important location for leisure activities (Genoe, 2009), enhancing people's quality of life (Brod et al, 1999), and strengthening self-identity for younger people with dementia (Olsson et al, 2013). Nature and the environment was also a strong source of hope elsewhere in other populations such as healthy educators (Hick's, 1998) and people with a first recurrence of cancer (Herth, 2000).

Another difference was that hope in this study could be generated in people with dementia from reminiscing about the past. This has implications for reminiscence therapy which perhaps inadvertently creates hope, although this has not been recognised before. This is supported by

the work of Lopez et al (2000) whose hope enhancement techniques include 'looking for positive stories', supporting people in recalling how they overcame obstacles in the past to create a hopeful attitude in the present.

Participants in this study did not just draw on hope from the past however, they also looked to the future. In contrast to Chapman's (2011) study, participants remained goal-directed, describing numerous targets they planned to meet and events that they were looking forward to. As the participants in this study were younger than in Chapman's (2011) it is possible that this represents an age effect (younger people perhaps experience more goal directed hope), but this is not possible to determine without a larger scale study. As there was also no control used in this study, it is not possible to determine whether this their hope was more or less than other people of their age. Another possibility for the difference in findings is that perhaps participants in Chapman's study were unable to recall goals when asked directly, feeling put on the spot, and the methodology used in this study (photographs and partners to support the person's memory) made goals easier to elicit.

As found by Radbourne (2008) and Genoe (2009), most participants hope was initially weakened when the dementia diagnosis was given, but strengthened over time as they gradually came to terms with their situation. People adapted to changes in their illness (Genoe, 2009), developing strategies to help themselves (Clare, 2002; Genoe, 2009) and kept busy (Radbourne, 2008). There was none of the hopelessness and sense of futility that Svanström and Dahlberg (2004) reported, and they proved that they were in fact quite able to develop coping strategies.

Although participants identified barriers to their hope, on the whole they did not appear to be struggling to keep despair at bay in contrast with previous work (Radbourne, 2008; Genoe, 2009; Genoe & Dupuis, 2014; Wolverson et al, 2010; Clare, 2002). The exception was Matthew who found himself overcome with emotion when he met ex-students and their families, and he struggled considerably to stay positive at this time. He had been diagnosed the most recently of all the participants and was still very much grieving and struggling to come to terms with his illness, which perhaps could explain this difference. Also perhaps, each encounter brought him face to face with societal views of what living with dementia meant, which challenged his hopeful view of a life worth living.

All six participants had a very striking internal locus of control, exemplified in the overarching theme 'defying dementia'. As in Radbourne's (2008) study, hope was something that they actively sought, rather than passively waited for. As Rachel had said "*you have to create it for yourself*". There were also parallels with the ideas of resistance (MacKinlay, 2012), fighting spirit (Clare, 2002; Phinney et al, 2007; Genoe & Dupuis, 2014) conspiracy of hope (Deegan, 1996) and the

*“defiant power of the human spirit”* (McFadden, 2004). Participants fought the low expectations placed on them (including their own initial expectations of what was possible) and in this way they displayed ‘militant optimism’ Bloch (1971). Genoe & Dupuis (2014) similarly found that participants resisted *“the negative doom”* (p17) associated with dementia, and had hopes, aspirations and dreams.

At times however participants were more dependent on others to support their hope. As seen elsewhere people valued contact with their family (Snyder, 2001; Radbourne, 2008). The relationships that Rachel and Ann had with their support workers was clearly hope inspiring, and Robert found seeing his Consultant helpful, in line with Gavan’s (2011) view of hope inspiring relationships. It was unclear whether the professional’s own hope was important, as participants spoke much less about professionals than expected. Most had considerably more contact with professionals through a local charity than they did through the health service, who saw people six monthly in a clinic setting. Two people had been discharged from the latter, and no participants had a community mental health nurse or occupational therapist. It is possible that the importance of professionals would have been different if participants were in a different setting; for example a care home with more staff contact.

Another possible explanation for professionals having less influence on hope than expected comes from Repper & Perkins (2008) who, while acknowledging that professionals can foster people’s hopes, believe professionals to be not that important to people with mental health problems; *“relationships with mental health professionals are not ones from which most people derive their sense of meaning and value; few people see their purpose in life as to be a mental patient”* (p7). Perhaps therefore participants found greater meaning elsewhere; in holidays, hobbies, and being in nature, while this was something that they were still able to do. Where their local charity assisted with access to enjoyable experiences this enhanced hope.

Recovery approaches emphasise the importance of peers, and as Beard and Fox (2008) found, many people with dementia also value this and it brings them hope. This study broadly supports this finding, with several participants having said how their hope was boosted by being with other people with dementia, because as Ann had said ‘we’re all the same’, and she enjoyed giving and receiving advice as part of a reciprocal relationship. At times there were also hints of what Clare et al (2008b) called ‘collective strength’.

Most participants were not religious, but Rachel and Richard drew strength from their faith and spirituality (Snyder, 1999; MacKinlay, 2012; Stuckey, 2003). Not specifically from prayer however unlike Beucher & Grando (2009) or explicitly from by living according to Christian values



(MacKinlay, 2012). Nor did either describe their situation being part of a 'divine plan' (Dalby et al, 2012).

## 5.4 Barriers to People with Dementia Feeling Hopeful

Previous studies have shown that living with dementia can be hope hindering (Nygård & Borell, 1998). Genoe & Dupuis (2014) for example found that this was due to the changes dementia brought. There was evidence in Matthew of the 'frightening awareness' and 'disquieting emotions' they described in their own participants. There was also evidence of 'muddled thinking', 'fluctuating abilities' and 'draining energy' they described in Rachel, but she denied that this affected her hope as she was able to use coping strategies such as meditation to counter her symptoms.

Illness progression surprisingly did not preoccupy participants (unlike Norman et al, 2004), but the burden that this might one day create for others did (as in Radbourne, 2008) and worry over increased dependency was voiced. The everyday experience of living with dementia did not appear 'hellish' (Hulko, 2009) or 'devastating' (Davis, 1989; Scheider, 2006), and none of the participants were bitter or resentful (in contrast to Kiyak, 1988) powerless (Harris, 2002) or lost (Svanström and Dahlberg, 2004). As with several participants in Beard & Fox's (2008) study, Matthew suffered angst over not having access to research studies, feeling left out. In this way research proved to be a barrier to his hope rather than being hope enhancing.

Hope was lost at times, most dramatically when personhood was threatened (when treated like an object, or when others were rude and ignored their feelings) or when the person felt abandoned or alone. Also noted was that often an unequal power relationship was also present at these times, highlighting the political nature of hope. When they felt supported and self-identity was preserved, participants seemed able to resist threats to their hope. They were often surprised at what they were able to achieve and enjoyed exceeding their own expectations and those of others.

## 5.5 Reflections on Power Dynamics and the Voice-Centred Relational Method

The Voice-Centred Relational method (Brown and Gilligan, 1992) used to interpret the data proved to be an effective and easy to use framework, despite being time intensive. It was particularly effective at detecting power relationships between participants and their partners, who had been present at all interviews except Rachel's (who was single). There were for example several instances of partners answering questions on behalf of participants, or correcting their mistakes. At times Ann did not want this help from her husband. On one occasion she shouted; *"no go away!"* when he attempted to identify a photograph for her, and on another occasion, learning that he had used the camera without her permission she said; *"did you do that?...the picture of my dad? Why did you do that? ...fool...fool"*.

However how participants responded generally was revealing. Rarely (aside from the above) did they appear upset, offended, or belittled by these interventions, and equal power in the relationship was maintained. Richard for example did not defer to his wife, but asked her for information in a matter of fact way; *"you remember where that one was?"*. This assistance meant a lot to him and on no fewer than four occasions he said, beaming with pleasure (rather than sadness or resentment); *"I had forgotten that!"*. This practice of using partners as a resource is reminiscent of Swaffer (2012), a blogger with young onset dementia who has referred to her husband as the 'BUB', or 'back up brain'. She says with clear parallels to Richard's experience; *"he does not take away my dignity and power to do things for myself, but instead assists me from the side lines...my back up brain, my hard drive, the one that is fading, but with effort, and sometimes assistance, can still function well"* (Swaffer, 2012). Hyden (2011) has also described something similar; 'scaffolding' where joint story telling takes place.

Participants employed different strategies to deal with power imbalances to prevent loss of hope. Rachel described psychologically 'shutting down' and remaining silent when she was not being listened by a doctor, and Ann put physical distance between herself and her mother in order to cope. Matthew had tried to ask questions when he was diagnosed with Alzheimer's to take back control, but found himself unable to do so. He suspected that his medication was a placebo, but took it anyway and harboured his suspicious thoughts, psychologically distancing himself from professionals. None of the participants reported feeling obliged to be hopeful, that hope was a burden.

## 5.6 Individual Variations

Each participant described hope in their own way, according to their personalities, preferences and life stories, which was in line with previous work on phenomenology and the lived experience. Richard often played the role of host, using story-telling and anecdotes to entertain during the interview, and sometimes educate. Robert meanwhile used the photography task to document his work, and proudly produced albums demonstrating his gardening achievements over the years. This reminiscence clearly brought him great joy and strength. The only females, Ann and Rachel spoke more openly about emotions, both describing how dementia had affected them with great articulateness and insight. Rachel was particularly detailed about why she had selected particular subject matter and how it related to hope. Whether this ability to talk about hope more directly represents a gender difference is an interesting question that would be worthy of further study.

Because of the geographical closeness of many participants, the same subject matters was mentioned by more than one person, and for each it had a different meaning. For Rachel a local museum was where she was able to be creative and mixed with other people with dementia, but for Ann it was about the unusual exhibits. For Robert a building damaged by fire was where he had his wedding reception and he did not comment on the damage when took pictures of it on his anniversary. For Rachel however the hotel held no memories and it was instead a symbol of mankind rebuilding from the ashes. In this way participant's attached individual meaning to subject places and situations (rather than them having an innate meaning) in line with social constructionist theory.

While none of the participants had adopted the 'sick role', some people had come to terms with and integrated dementia into part of their identity more than others. The two women, Rachel and Ann, both saw it as part of who they were, and as a way of meeting people, and building connections. Matthew in stark contrast found meeting other people with dementia horrifying, and it scared him because in them he saw his own future. As mentioned earlier the fact that he had had less time than the others to adjust may have been relevant. James meanwhile appeared to have almost put psychological distance between himself and others with dementia; *"no I felt I felt that um they were....they were in a late stage really yeah...there's nobody at home I think they they um...fine you know if if I end up in that stage then I won't know much about it anyway"*. Quite the opposite to Matthew seeing people with dementia brought him some degree of reassurance; *"it was good in one respect...in one respect I felt a bit (chuckles) better about it because I realised that there's peop...a lot more people who are um in a worse case, a worse situation"*. There did appear to be a greater degree of acceptance of their illness by people with dementia who had

been diagnosed the longest, and Matthew, who was the youngest did seem to have the highest levels of hopelessness at times, suggesting that age at diagnosis, as well as time since diagnosis may be a factor. As this is a very small scale study it is not possible to come to firm conclusions about this however.

### 5.7 Conclusions

This study supports the growing body of evidence that hope is important to younger people with dementia, and that recovery principles are worthy of further study with this client group. This study appears to be the first to observe that the hope people with dementia express may not always be expressed directly, and can also be expressed indirectly through metaphors, storytelling and reminiscence, or described instead as happiness or enjoyment. It also makes an original contribution by finding that there were individual differences in the way that people talked about hope according to their personalities, interests and social circumstances. People hoped for a future, and five themes in particular were elicited; good health for themselves and others; for enjoyable events to take place; for continued contact with other people; for success in their endeavours; and for a better world. This broadly supported findings from previous studies.

The photo diary methodology was effective in eliciting rich data about where people's hope came from. Four themes identified as sources of hope were; the surrounding environment; from 'taking action'; from the person's own internal resources, and from keeping connected to others. An over-arching theme was 'defying dementia', and participants lived life to the full, challenging negative stereotypes. These findings were again broadly similar to previous work, however this study found a greater importance of hope enhancing environments than has been seen before, and people also appeared to create hope through reminiscence which has not been previously described in people with dementia.

Living with dementia did not destroy people's hope, although it could be weakened significantly at the point of diagnosis. As people accepted and adapted to life with dementia hope was strengthened. Hopefulness was strongly linked to resilience and was employed as part of a strategy to deal with the challenges that participants faced. Hope came largely from within people with dementia, however others could impact on the level of hope that they felt. Hope was particularly threatened when people felt abandoned, isolated or 'cast adrift' by services, especially if their personhood was threatened.

## 5.8 Implications for Practice

This study is one of the first to investigate the views of younger people with dementia about hope. It has shone light on what might make people feel both more, and less hopeful, important for working in mental health services where hope might be seen as an important goal in recovery. The visual model of hope sitting within an ecosystem may be a useful way of taking the concept of hope forwards in clinical practice. By emphasising the importance of a supportive surrounding environment, and of ensuring that the person has opportunities to take action, staff can nurture hope and visualise this process better.

Healthcare staff should be aware that cognitive enhancing medication and research opportunities are not necessarily a key source of hope for younger people with dementia living at home, and that inconsistent messages about these can lead to disappointment and reduced hope over the longer term. Particular care should be taken of the person's psychological needs during the diagnostic period, a critical time when people may feel hopeless. Increased support should also be considered at this time, and as Matthew said this need not be time intensive; *"a phone call...just one phone call...even if it's just saying 'Hi...it's me...I'm just phoning to say...you know...how you doing...' da da da"*.

Professionals can also support people's hope by encouraging them to maintain supportive networks, and to draw on their existing strengths and coping strategies. Interactions with people with dementia should be person-centred, with power imbalances minimised. Exposure to hopeful environments should be encouraged, and the following question posed by Deegan (1996) should be considered; *"how do we create hope filled, humanized environments and relationships in which people can grow?"* (Deegan, 1996, p2).

As many participants found the photo diary task enjoyable and even hope enhancing in itself, this raises the possibility that the task could be adapted and used as a therapeutic intervention in its own right. Further research is needed to ascertain whether this would be useful, and whether more broadly hope should be a bigger part of what professionals discuss with people with dementia. Similarly more research is needed to determine whether reminiscence could be used as a more targeted way as a hope intervention, and what form this might take.

## 5.9 Strengths and limitations

The methodology was successful in generating sufficient rich data, and this study has added to what is already known about hope in younger people with dementia. Participants reported that the cameras were easy to use and they able to them independently, with the exception of Ann whose husband supported her at times. The photographs served as useful memory aids for participants during the interviews, and many people expressed pleasure when photographs came out well. Richard for example gushed; *“now this is a spectacular picture”, “a real capture”, “now that’s a really good one isn’t it?” and “it’s a lovely picture that one...really nice...that’s really nice”*. For him the task was clearly a very positive experience in itself; *“I’m really glad we took that ‘cause it’s terrific...I remember it so clearly...this is spectacular”, “I think it might be worth having a little frame for it” and “definitely uplifting to look back on it”*. Richard used two cameras due to his enthusiasm, and Robert used older photographs from an album to support his narrative during the interview. Matthew meanwhile felt that the task had made him more mindful of what made him hopeful and had been making more of a conscious effort to incorporate this more into his life, which brought satisfaction as a researcher:

*“I do lots of things that I think things we talked about...on there...and, I love that bit. I love, you know, being out...by...we’ve...we’ve started doing things and, I can’t remember if that was before or after...So...that sort of pushed us on to do something which I guess wasn’t a part of that at all but it’s been really quite nice hasn’t it? it’s been really nice”*

Matthew

Limitations were that occasionally indoor photographs were very dark when developed making identification more difficult. Rachel also sometimes forgot to take the camera out with her, but was able to use her own camera instead, as she tended to always carry it. The study had a small sample size (n=6), which included only two women. There was also some homogeneity in that all participants appeared middle class, most were in their 60s and all were in the earlier stages of their illness, and it would have been interesting to how different demographics affected the person’s experience.

Some participants found hope hard to define, which made taking photographs more challenging. Matthew said; *“it’s difficult...to... (knocks on table) ...box it...”* and Ann agreed; *“it was quite difficult”*. Matthew took only two photographs for this reason, but after spending some time discussing hope with his wife prior to the interview he felt that he had gained a better understanding. It was unclear at times whether participants were describing hope, happiness or coping as these concepts were used interchangeably. The broader hope literature supports the notion that hope is hard to define however, and so this is not unique to people with dementia.

## Appendices





## Appendix A Example of critical appraisal

Author(s)	Aims of research	Research design	Research design addressed research aims?	Recruitment strategy - appropriate to aims?	Data collected in a way that addressed research issue?	Relationship between researcher & ethics	Data analysis rigorous?	Findings	Value of research to this study
Aminzadeh et al (2007)	To examine the emotional impact of disclosure of a dementia diagnosis on PWD both from their perspectives and those of their caregivers	Qualitative. Participants n=30 couples attending a Day Hospital in Canada. All participants were over 65 years. Data source were: (a) audio-tapes of diagnosis disclosure meeting, (b) in-depth interviews with PWD & caregivers within one week of disclosure (c) focus group interviews with caregivers within one month.	? – Researchers do not justify the research design, but appears effective in addressing aims of the research. Several different methods of data collection used	Yes broadly – person-centred approach used. Recruited through day hospital. No mention of any people who dropped out or declined to take part.	Yes - Recorded diagnosis meetings to obtain data at the time of diagnosis	Not known to each other prior.  No Ethical concerns. Ethical approval obtained. Capacity assessed. Approached prior to meeting when diagnosis given.	Yes - Data analysis software (Nudist, N6) was used. Work of Strauss & Corbin (1998) guided the analysis process. Frequent research meetings held to review conceptual codes	3 types of emotional response seen; denial/lack of insight, grief, and positive coping responses.  Ways that professionals could instil hope were described	Canada. Triangulated data from several different sources. Gives detailed practical suggestions about aspects of dementia that can be emphasised by professionals to instil hope (e.g. individual variations in illness). Older people only
Beard & Fox (2008)	To understand the social identity of people with dementia through examining the dynamics and context of focus groups	Qualitative. Part of 18-month ethnographic study. Interviews with N=32 PWD/MCI in focus groups and also interviews with N=8 PWD. All over 65 years old. Most were men. Convenience and snowball sampling.	? - Researchers do not justify the research design, but appears effective in addressing aims of the research.	Yes broadly - no mention of any people who dropped out or declined to take part.	? – setting for data collection was not explained or justified but appeared to	Relationship between researcher & participants not discussed.  No Ethical concerns. Ethical approval obtained.	Yes – constant comparative method of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1997) was used	Many respondents reportedly suffered angst over not having access to studies they <b>hoped</b> could help them.	USA. Older people only. Little detail given about hope and this was no primarily what was being studied



## Appendix B Ethics Committee approval letter NRES

  
**Health Research Authority**  
**NRES Committee East of England - Norfolk**  
 The Old Chapel  
 Royal Standard Place  
 Nottingham  
 NG1 6FS  
 Telephone: 01158839390

07 January 2015

Mrs Jane Pritchard  
 Nurse Consultant  
 Northamptonshire Healthcare NHS Foundation Trust  
 Younger people with dementia team  
 The Rushden Centre  
 Newton Road, Rushden, Northants  
 NN10 0PT

Dear Mrs Pritchard

**Study title:** An exploration of the perceptions of younger people with dementia about hope

**REC reference:** 14/EE/1277

**Protocol number:** N/A

**IRAS project ID:** 159343

Thank you for your letter of 6th January 2015, 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Assistant, Tad Jones, [NRESCommittee.EastofEngland-Norfolk@nhs.net](mailto:NRESCommittee.EastofEngland-Norfolk@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Mental Capacity Act 2005**

The committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project.

#### **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>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**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).**



### 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).

#### Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [flyer]	Version 3	25 November 2014
Interview schedules or topic guides for participants [question prompts]	Version 2	22 November 2014
IRAS Checklist XML [Checklist_20112014]		20 November 2014
IRAS Checklist XML [Checklist_22112014]		22 November 2014
IRAS Checklist XML [Checklist_26112014]		26 November 2014
IRAS Checklist XML [Checklist_30122014]		30 December 2014
IRAS Checklist XML [Checklist_05012015]		05 January 2015
IRAS Checklist XML [Checklist_06012015]		06 January 2015
Letter from sponsor [letter ERGO]		06 October 2014
Letters of invitation to participant [initial invitation letter]	v3	30 December 2014
Other [Ruth Bartlett CV]	Version 1	22 November 2014
Other [Indemnity certificate]	Version 1	22 November 2014
Other [Expression of interest form]	Version 2	25 November 2014
Other [Recruitment flyer for staff]	Version 1	24 November 2014
Other [Participant info sheet]	V3	05 January 2015
Participant consent form [consent form]	Version 2	22 November 2014
Participant information sheet (PIS) [camera instruction]	Version 2	22 November 2014
REC Application Form [REC_Form_30122014]		30 December 2014
Referee's report or other scientific critique report [Peer review]	1	07 August 2014
Research protocol or project proposal [Protocol]	Version 2	22 November 2014
Summary CV for Chief Investigator (CI) [CV]	Version 2	22 November 2014
Summary CV for student [CV]	Version 2	22 November 2014
Summary CV for supervisor (student research) [CV Prof Judith Lathlean]	Version 2	22 November 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol]	Version 2	22 November 2014

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Training

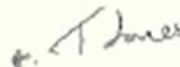
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/EE/1277

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Michael Sheldon  
Chair

Email: NRESCCommittee.EastofEngland-Norfolk@nhs.net

*Enclosures:* "After ethical review – guidance for researchers" [SL-AR2]

*Copy to:* Ms Diana Galpin  
Mr Stephen Zingwe, Northamptonshire Healthcare NHS foundation Trust





## Appendix C Ethics Committee approval letter University of Southampton (ERGO)

### Research Governance Feedback on your Ethics Submission (Ethics ID:9926)

ERGO [ergo@soton.ac.uk]

Sent: 06 October 2014 14:58

To: Pritchard J.C. (PGR Student)

Submission Number 9926:

Submission Title An exploration of the perceptions of younger people with dementia about hope:

The Research Governance Office has reviewed and approved your submission

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external ethics review (e.g. NRES). The following comments have been made:

"

Submission ID : 9926

Submission Name: An exploration of the perceptions of younger people with dementia about hope

Date : 06 Oct 2014

Created by : Jane Pritchard

I am writing to confirm that the University of Southampton is prepared to act as Research Sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005). We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

[http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/Researchgovernance/DH\\_4002112](http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/Researchgovernance/DH_4002112)

If your study has been designated a Clinical Trial of an Investigational Medicinal Product, I would like to take this opportunity to remind you of your responsibilities under Medicines for Human Use Act regulations (2004/2006), The Human Medicines Regulations (2012) and EU Directive 2010/84/EU regarding pharmacovigilance. If your study has been designated a 'Clinical Investigation of a Medical Device' you also need to be aware of the regulations regarding conduct of this work.

Further guidance can be found:

<http://www.mhra.gov.uk/>

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

Please also familiarise yourself with the Terms and Conditions of Sponsorship on our website, including reporting requirements of any Adverse Events to the Research Governance Office and the hosting organisation.

If your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available. Please also be reminded that you may need a Research Passport to apply for an honorary research contract of employment from the hosting NHS Trust. Both our Terms and Conditions of Sponsorship and information about the Research Passport can be found on our website:

<http://www.soton.ac.uk/corporateservices/rgo>

Failure to comply with our Terms may invalidate your ethics approval and therefore the insurance agreement, affect funding and/or Sponsorship of your study; your study may need to be suspended and disciplinary proceedings may ensue.

Please do not hesitate to contact this office should you require any additional information or support.



## Appendix D      Permission to undertake research NHFT

Northamptonshire Healthcare   
NHS Foundation Trust

**Research and Development**

Carey Block  
ST Mary's hospital Kettering,  
Northamptonshire  
NN15 6XR

Direct Dial: (01536) 452303

**Medical Director:** Dr Alex O'Neill-Kerr  
**Head of R&D:** Sue Palmer-Hill  
**Interim R&D Manager:** Leanne Holman

15<sup>th</sup> January 2015

Mrs Jane Pritchard  
Nurse Consultant  
Northamptonshire Healthcare NHS Foundation Trust  
Younger people with dementia team  
The Rushden Centre  
Newton Road, Rushden, Northants  
NN10 0PT

Dear Jane

I am pleased to confirm that with effect from the date of this letter, the above study now has Trust Research & Development permission. You can now commence your research activities in Northamptonshire Healthcare NHS Foundation Trust in accordance to the agreed protocol and the Research Governance Framework.

<b>Title</b>	<b>An exploration of the perceptions of younger people with dementia about hope</b>	
<b>REC Ref:</b>	14/EE/1277	<b>NHFT Ref:</b> R:225
<b>IRAS Ref:</b>	159343	
<b>Service Area</b>	Dementia	
<b>Start date</b>	15 <sup>th</sup> January 2015	<b>End date:</b> 29 <sup>th</sup> August 2016

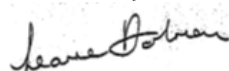
The Department of Health through East Midlands Clinical Research Network expects you to consent the first research participant within 70 days from the date of valid application submission. Please provide us with the date of the first participant recruited in due course.

As part of our monitoring requirements you are required to submit a six months progress report to the R&D Office and to the Research Ethics Committee from the start date. We ask you for a summary report of your study findings upon completion of your research as we would like to disseminate in within the Trust.

If you have any questions regarding this, or other research you wish to undertake in the Trust, please contact this office. We wish you every success with your research.

*Please be aware that any changes after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust*

Yours sincerely



Leanne Holman

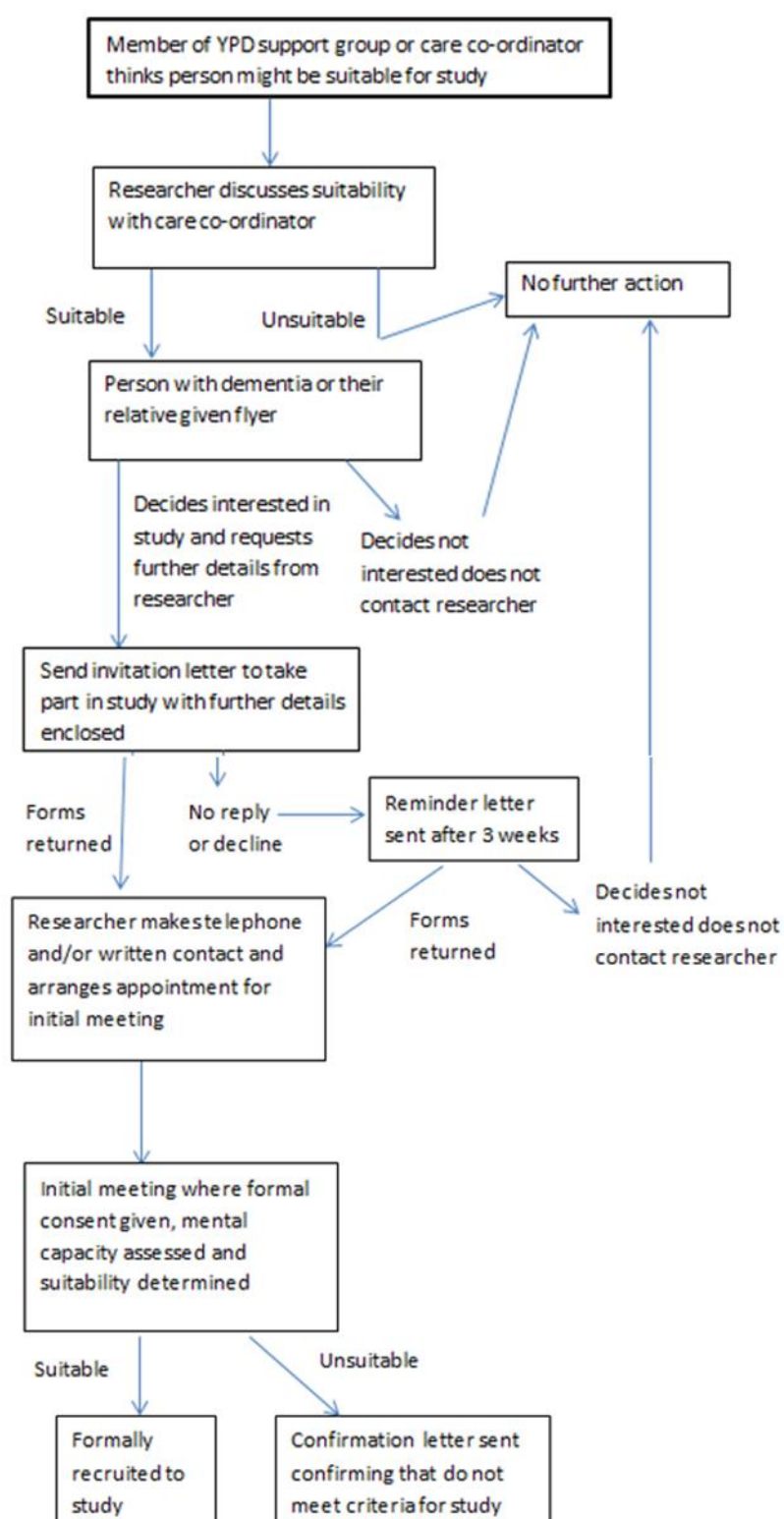
Research and Development Manager

## Approved documents received:

Document	Date	Version	Date REC approved
REC favourable opinion	07 January 2015		
Copies of advertisement materials for research participants [flyer]	November 2014	Version 3	07 January 2015
Interview schedules or topic guides for participants [question prompts]	22 November 2014	Version 2	07 January 2015
Letter from sponsor [letter ERGO]	06 October 2014		07 January 2015
Letters of invitation to participant [initial invitation letter]	30 December 2014	v3	07 January 2015
Ruth Bartlett CV	22 November 2014	Version 1	07 January 2015
Indemnity certificate	22 November 2014	Version 1	07 January 2015
Expression of interest form	25 November 2014	Version 2	07 January 2015
Recruitment flyer for staff	24 November 2014	Version 1	07 January 2015
Participant info sheet	05 January 2015	V3	07 January 2015
Participant consent form [consent form]	22 November 2014	Version 2	07 January 2015
Participant information sheet (PIS) [camera instruction]	22 November 2014	Version 2	07 January 2015
Referee's report or other scientific critique report [Peer review]	07 August 2014	1	07 January 2015
Research protocol or project proposal [Protocol]	22 November 2014	Version 2	07 January 2015
Summary CV for Chief Investigator (CI) [CV]	22 November 2014	Version 2	07 January 2015
Summary CV for student [CV]	22 November 2014	Version 2	07 January 2015
Summary CV for supervisor (student research) [CV Prof Judith Lathlean]	22 November 2014	Version 2	07 January 2015
Summary, synopsis or diagram (flowchart) of protocol in no-technical language [Protocol]	22 November 2014	Version 2	07 January 2015

Please note that some of the documents may not apply to your study.

## Appendix E Flow chart of recruitment process







## Appendix F Flyer for recruitment of participants


Version 1 Created 24/11/14 Jane Pritchard

Northamptonshire Healthcare **NHS**  
NHS Foundation Trust

UNIVERSITY OF  
Southampton

### Research Recruitment

**Do you know someone with dementia who would like to talk about their views on hope?**



This project is part of the Clinical Doctorate I am currently studying for at Southampton University. I want to understand what younger people with dementia think about hope, in order to improve the way that we work with people. I need your help in recruiting people to the study. I am looking for 6 people with dementia to take part.

### What will happen?

I would be grateful if you could identify people from your caseload who might be suitable to take part. We can then discuss whether they meet the criteria, and I have flyers that suitable people can be given. If they are interested in taking part there is some more detailed information I can send. I need to meet the person initially to assess their capacity to take part, then meet twice more when we will talk about hope. I will give the person a disposable camera to take pictures of what makes them feel hopeful so that I can better understand what helps them.

### Who can take part?

To take part the person must:

- Have been formally diagnosed with dementia (any type)
- Be between 18-65 years of age
- Live in their own home (can be rented or local authority owned)
- Be able to speak good English
- Have good enough eyesight to take photographs
- Have good enough hearing to be able to hold a good conversation

### Where can I get more information?

**Post:** Jane Pritchard Nurse Consultant, YPD Team, Rushden Centre, Newton Road, Rushden, Northamptonshire, NN10 0PT

**E-mail:** Jane.pritchard2@nhft.nhs.uk      **Telephone:** 07771387127





## Appendix G Initial invitation letter

Initial invitation letter

YPD Team  
The Rushden Centre  
Newton Road  
Rushden  
Northamptonshire  
NN10 0PT  
  
Tel: 07771387127

(insert date)

Dear (insert name)

**Re: Research study; perspectives of people with dementia about hope**

Thank you for your interest in taking part in this research study. My name is Jane Pritchard and I am writing to give you more information about this study so that you can decide if you would like to take part. I work with people with dementia in Northamptonshire as a nurse, and this project is part of my doctorate which I am studying for at the University of Southampton.

The project will be looking at 'hope', from the point of view of younger people with dementia. This will help staff better understand how people feel, and how they might help people with dementia feel hopeful. There are no right or wrong answers; I'm just interested in your opinion. Participation in the project is completely voluntary and you are under no obligation to take part. If you would like to take part please complete the enclosed form and return it in the pre-paid envelope. You can change your mind at any time.

*Version 3 Created 30/12/14 Jane Pritchard*

### What will be involved?

I enclose a copy of the participant information sheet which gives further details of the study.

- **Initial meeting** - you are welcome to have someone with you. At the meeting I will answer any questions you might have about the project. I will also ask you some questions to make sure that you understand what is involved and that you meet the criteria for the study. If you are still happy to take part and meet the criteria, you will be asked to sign a form that says you consent to taking part. You will then be asked some general questions about you and your life in order that I can understand a bit more about you as a person. A time and place for the next meeting will then be set for the next stage. You can change your mind about taking part in the study at any time.
- **Second meeting** – we will meet again at a time and place of your choice. Again you can have someone with you. I will make sure that you still want to take part, and if you do I will give you a disposable camera and show you how to use it, and leave you with some instructions to remind you before I leave. You will be asked to take pictures of things that make you hopeful and we will look at the pictures you took at our next meeting. I will pay for the processing of these pictures and they are yours to keep afterwards, I will not keep copies myself. I will keep in touch with you to see how you are getting on with taking your photographs. When the photographs have been processed and you have them back we will arrange to meet again final time.
- **Final meeting** – Again I will make sure that you are happy to take part. Our conversation will last for about an hour, if this is too long we can make breaks in between, or we can continue the interview on another day. We will look at the photographs together and discuss them. You will be asked about your experiences of living with dementia, in particular about what hope means to you and if it is important to you to have hope. Our conversation will be *audio recorded* (using a digital Dictaphone) to ensure that I don't miss anything important that you say. I may also make some written notes. You can still change your mind about taking part at any time, and I will stop the interview if you need a break, or feel you don't want to continue. Remember there are no right

or wrong answers, and this is not a test. It doesn't matter if you feel hopeful or not, I am still interested in what you have to say.

**What do I do now?**

If you would like to take part in the study please complete the attached form and send it back to me in the pre-paid envelope provided. Please make sure you have indicated how you would prefer me to contact you and have provided contact details. The meeting will be held wherever you feel the most comfortable, it could be at your home, the home of a relative or on NHS premises. I will also give you a choice of days and times and will try to fit around you as much as possible.

If you don't want to take part on this occasion then please either indicate this on the form and send it back to me, or do nothing, and I will presume that you have chosen not to take part.

If you have any questions in the meantime please feel free to contact me on the number at the top of this letter, or write to me at the address given.

Yours sincerely

Jane Pritchard

Nurse Consultant of the Younger People with Dementia Team in Northamptonshire and Doctoral Student, University of Southampton



## Appendix H      Instructions for camera task

### Camera Task – Things that make you hopeful

Your task is to take photos of things that make you feel hopeful. You have been given a camera which takes (insert number) pictures to do this with. You don't have to pay for these to be developed, this will be done for you. You can keep all of the photos afterwards.

It's up to you what you take photos of, it should be your choice. If you need someone to help you work the camera this is fine (they can be tricky!)

If you need some inspiration, others have taken pictures of:

- Nature
- Weather
- Things in your home
- People
- ✓ • Pets
- Hobbies
- Everyone is different think of what is important to you

### Please don't take photos of:

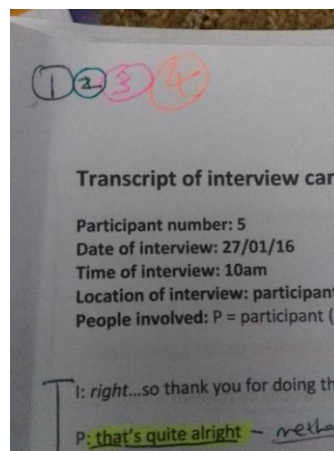
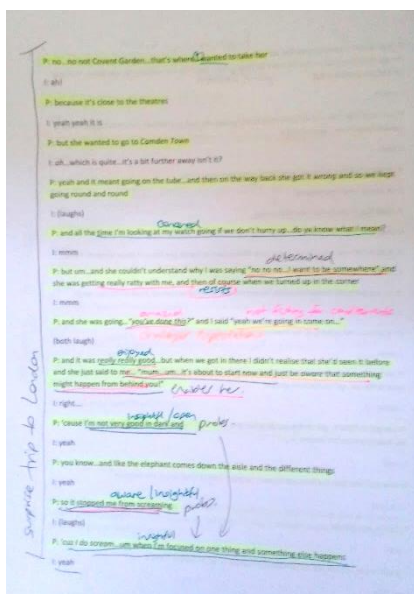
- Anyone who doesn't want their photo taken
- Anyone who hasn't given you their permission
- ✗ • Intimate body parts
- Anything that puts you in danger

Happy snapping! Please contact me when you have taken all of your photos

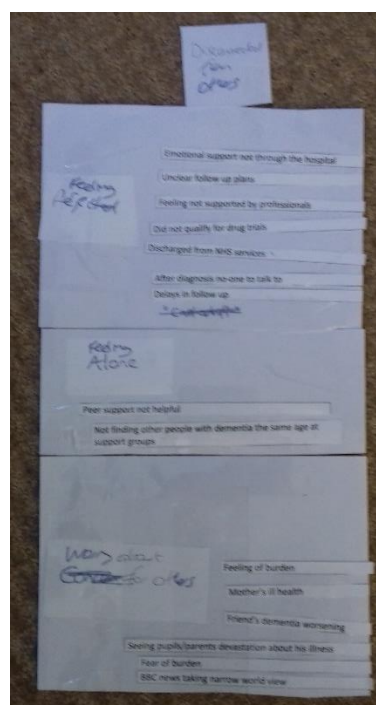
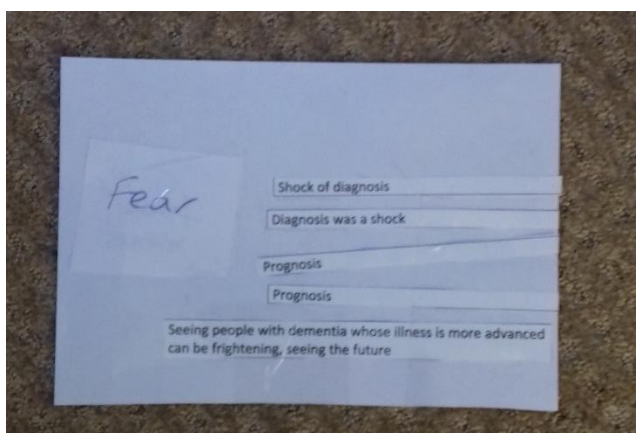
Jane



## Appendix I Examples of data coding



(Above) part of a transcript showing analysis using the Voice-Centred Relational Method. The words of the person with dementia were highlighted in yellow. Different coloured pens were then used to make notes during each of the four stages of the analysis. An asterisk was placed next to the word 'hope' when it was used, and particularly relevant sections were underlined. (Below) data relevant to the research aims (e.g. uncovering barriers to hope) was extracted, summarised on slips of paper and then arranged into themes. 'Fear' was a lower order theme for example (see below). Slips of paper were secured to larger pieces of paper with sticky tape once the process was complete. Lower order themes were then analysed and higher order themes generated from these. Appendices J, K and L show the full results once data was transferred into tables.







## **Appendix J      What participants hoped for**

Summary	Lower order theme	Higher order theme
Improvement in illness or for plateau	Illness stabilisation	Good Health
Meditates in the hope that her mind will become clearer when feels overwhelmed		
Medication helping		
Health stabilisation		
Delay in illness progression		
More years when able to visit theatre and other places		
For illness to not get any worse		
Their children getting on well in life	Other’s health and wellbeing	
That husband will stop smoking		
Sick tree living		
Garden growing		
That others don’t have too many stairs to climb		
That a cure for dementia would be found	Cure for dementia	
Good weather	Good weather	Enjoyable Events
Having grandchildren	Additions to family	
Buying puppy		
That next dementia café as good as last time	Enjoyable evening at dementia cafe	
Looking forward to going on holiday	An enjoyable holiday	
That friend enjoys DVD	Bringing joy to others	
Others pleasure when see photographs		
Hearing from friend	Friends	Contact with Others
Contact with friends		

Seeing family	Family	
Seeing support worker	Support worker	
Being reunited with loved ones in the afterlife	Reunited in afterlife	
Garden growing well and good flowers	Successful garden	Success in Endeavours
Team winning rugby	Rugby team winning	
Completing family tree	Completing project	
Can take a good picture	Being creative	
The opportunity to be creative in the snow		
Finding the right place to make mosaics		
Corporations being broken up	A fairer society	A Better World
Mankind will realise they can't control the weather and that house building will reflect this/respect nature/being in balance	Respecting nature	

## **Appendix K      What made participants hopeful**

Summary	Lower order theme	Higher order theme	
Appreciating daffodils growing	Nature	Environmental	
Watching the birds in the garden			
Appreciates view from house of the horses			
Enjoying the seasonal plants			
Views of nature from the house			
Beautiful sunset			
View of mountains from hotel			
Beautiful flowers			
Beautiful gardens			
Enjoying the sunshine			
Enjoying the countryside			
Enjoying own garden			
Beauty of trees in autumn colours			
Picture of the woods			
Appreciating music	Sensory Experiences	Environmental	
Eating delicious food			
Loves colours			
Enjoys feeling tactile objects			
Sensation of water and wave machine			
Feeling warmth from greenhouse			
Admiring cathedral architecture	Culture		Environmental
Watching rugby			
Admiring a fountain			
Appreciating music			
Looking around churches			
Enjoying the café experience			
Immersed in culture on holiday			
Admiring a statue			
Watching a live cricket match			

Going to the theatre		
Enjoying seeing strangers celebrate their wedding	Happiness of others	
Seeing the grandchildren happy		
Friend from football smiling		
Seeing wife happy		
Cathedral architecture and windows	Admiring the achievements of others	
Bridges and railways		
Taking part in research	Creating Legacy	Keeping connected
Pride in knowing that has helped his pupils to succeed in life		
Reminisces on helping during storm		
Teaching mosaics to other people with dementia		
Giving gifts	Giving gifts	
Giving away food to her neighbour		
Giving swing away		
Doing volunteer driving		
Bought DVD for a friend		
Helped son buy a flat		
Buying son a puppy		
Recalls helping son with his job	Helping and caring for others	
Supporting others at the Dementia Cafe		
Doing volunteering		
Enjoys taking care of cat		
Describes taking care of plant		
Upcoming family gathering	Actively maintaining relationships	
People in the walking group		
People at church		
Friends		
People through the local charity		

Dementia café friends	
Friends at cycling club	
Support worker	
Spouse	
Children	
Grandchildren	
Son-in-law	
Family	
Pets	
Other people with dementia	
Quality time with family	Spending quality time
Going away for weekend with wife	
Photo of rowing club	Belonging
Visiting old University is like going home	
Table tennis team have accepted and value him	
Part of a community at church	
Support network important	Having a support network
Granddaughter takes care of her	
Post-diagnostic support from charity	
“Strong family” behind him	
Family living nearby is a comfort	
Support worker	
Being seen in clinic by a professional	
Stays connected to family, looking forward to seeing them	
Husband supports her with shopping	
Peer support through walking group	
Where went to University	Places
Jersey	
Ireland	

Budapest			
Local stately home gardens			
Fond memories of where went to University and still enjoys visiting			
Friend arranged for him to see his old school			
Reminisces about happy Christmas in Prague			
Fond memories of Port Talbot			
Upcoming holidays			
Past successes - reminiscing about growing expensive begonias from tubers	Setting goals & looking ahead	Taking action	
Washing line project			
Garden boarder			
Rain gauge project			
Gravelled area			
Plants and pots			
Bird table			
Important to have targets to focus on			
Repotting			
Transformation of area			
Transformation of shed			
Cementing			
Cutting ivy by shed			
Working on the allotment			Keeping busy
Important to have things lined up			
Keeping up hobbies and interests			
Making a Buddha head out of snow	Being creative		
Making and selling mosaics			
Creating art in a group			
Having events to look forward to	New experiences		



Upcoming holidays		
Trying new things		
Seeing unusual flowers		
Visiting new places		
Discovering new music		
Unexpectedly meeting a Baroness		
Bumping into celebrities		
Doing things wife doesn't know about		
Broadening horizons		
Statue unexpectedly found		
Remembers helicopter landing		
Watching the crowd sit on the pitch during the break of a cricket match		
Enjoys that friends come up with "weird ideas" of things to do		
Enjoys the unusual things in museum		
Team winning rugby	Sporting and athletic achievements	
Reminiscing about rowing team		
Winning at table tennis		
Hiking to top of hill		
Teachers other people with dementia mosaics	Stretching self and others	
Playing table tennis		
Coaching self on MMSE to improve score		
Taking on dementia as a challenge		
Sticking out extended time in the head scanner		
Doing volunteer driving		
Challenging other people's perceptions of people with dementia		
Getting kit ready for walking	Keeping continuity	
Grounds of stately home nearby as somewhere to remember him		

Doing the housework		
Packing garden tools away each day		
Writing a diary everyday		
Reminding self that nothing has changed, still the same		
Keeping fit	Keeping healthy	
Walking		
Enjoying socialising		
Cycling		
Keeping independence		
Meditating		
Buying second hand furniture	Embracing the future	
Making garden manageable		
Converting the house		
Picture of rainbow	Being positive	Drawing on internal resources
Rain being good for the grass		
When it rains he measures it with his rain gauges		
Dislikes snow but opportunity to be creative		
Making a Buddha head out of snow		
Enjoys the fun and chaos the grandchildren bring	Fun and keeping a sense of humour	
Playing with cat		
Son-in-law is fun		
Dog has funny habits		
Playing joke on friend about 'Babe' film		
Joking with friends		
Making others laugh and keeping sense of humour		

Remembers with humour a spider jumping at her in the museum		
Recalls amusing sermon about feet		
Laughing at rude shaped plant		
Holiday friends were good fun		
Older friends were good fun		
Watching dogs is fun		
Watching horses can be fun		
Crosses are an important symbol for her	Strength from religion	
Promise of being reunited with loved ones		
Moves her when people are kind	Faith in human nature	
Making a mosaic dedicated to the people who died in the Paris bombings		
Flooding in fields as hoping man will realise can't control weather		
Hotel covered in scaffolding as being rebuilt after fire		
Pigeons that someone is making the effort to feed		
People cleaning a building as feel it's worth the time		
Modern sculpture juxtaposed with old buildings; harmony		
Cathedral well looked after over the years		
Taking on dementia as a challenge	Overcoming adversity	
challenges people's perceptions of people with dementia		
Doesn't believe in giving in		
Interested in David & Goliath mural – metaphor?		

Sticking out extended time in the head scanner			
Reminiscing about overcoming adversity in the past			
Fond of the ‘circle of life’ theme in the Lion King film	Seeing Regeneration		
The sun rising again in the morning			
Fond of the ‘Lion King’ story			
Picture of the woods – nature regenerating			
Regeneration/renewal of grass			
Appreciating spring plants coming through			
Hotel rising from the flames			
Seeing the world fresh and invigorated			
Cutting the grass is “ <i>what boys do</i> ”			Expressing identity
Proud of his “ <i>man shed</i> ”			
Pictures of his life created by his sister			
Reminiscing about rowing team			
Grounds of stately home nearby as somewhere to remember him			
Interest in bridges/engineers			
Interest in trains and railways			

## Appendix L      Barriers to hope

Summary	Lower order theme	Higher order theme
Diagnosis was a shock	Shock of diagnosis	Fear of dementia
Seeing pupils/parents devastation about his illness		
Poor prognosis	Thinking about prognosis	
Seeing people with dementia whose illness is more advanced can be frightening, seeing the future		
Expectations about medication dashed	Lack of effective treatment	
Simply measuring decline during follow up		
Parents behave negatively towards her	Experiencing stigma because of dementia	Threats to identity
Stigma about other people with dementia		
Spoken to disrespectfully; told repeating self		
Given diagnosis on open ward, no privacy	Diagnosis prioritised over personhood	
Diagnosis given in bed, no dignity		
Felt diagnostics took priority over welfare		
Medical teaching took priority over the person		
When diagnosed the clinic appointment felt rushed		
Given lumbar puncture without warning		
Denial that they have dementia	People denying they have dementia	
Fear of burden	Concern about being a burden	
Feeling of burden		
Discharged from NHS services	Feeling alone with dementia	Disconnection from others
Not finding other people with dementia the same age at support groups		

# Appendix J

Peer support not helpful		
Feeling not supported by professionals		
Did not qualify for drug trials		
Emotional support not through the hospital	Feeling unsupported by services	
After diagnosis no-one to talk to		
Unclear follow up plans		
Lack of joined up diagnostic process		
Not feeling listened to by professionals	Not feeling listened to	
Mother's ill health	Worry about poor health of others	
Friend's dementia worsening		
Delays in diagnosis	Delays in diagnosis and follow up	Frustrations & Restrictions
Delays in follow up		
Symptoms of dementia cause restrictions	Symptoms of dementia	
Lost confidence in going out alone		
Thought of not being able to achieve things		
Decline of steel industry which he loved		
Bad weather on holiday		
Bad weather stopped garden project		
The news is miserable		
Favourite programme cancelled		
BBC news taking narrow world view		

## **Glossary of Terms**





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