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Dementia, Vulnerability and Well-being:
Living Well with Dementia Together

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A report from the University of Manchester for Age UK and the Manchester Institute of Collaborative Research on Ageing (MICRA)[1]

[2] Dr Annie Austin is a Research Associate in the School of Social Sciences, University of Manchester
        (Lead/corresponding author, annie.austin@manchester.ac.uk)
Professor John O'Neill is Hallsworth Professor of Political Economy at the University of Manchester.
Professor Suzanne Skevington is at the Manchester Centre for Health Psychology and International Hub for Quality of Life Research (IHQoLR), University of Manchester.

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Executive Summary

This research examines the goal set out in the UK National Dementia Strategy that "All people living with dementia and their carers should live well with dementia". The findings show that it is undoubtedly possible to live well with dementia. 'Living well' is fundamentally a social idea, and the ability to *live well with dementia together* depends on both close personal relationships and the wider social environment.

The research suggests that social relationships are not only important in their own right, but are also catalysts for well-being in other aspects of life, including physical health and psychological well-being. Therefore, to enhance well-being and reduce vulnerability among people living with dementia, supporting relationships and social inclusion should be high on the policy agenda.

Background

There are an estimated 47.5 million people worldwide with dementia (WHO 2015), and this number is expected to double every 20 years (Alzheimer's Disease International 2015). In the UK, the number of people living with dementia is predicted to rise to one million by 2025 (Department of Health 2015), and in 2015 there were some 700,000 family carers who look after people with dementia (Alzheimer's Society 2015). In the context of an ageing population, supporting the well-being of people with dementia represents a central – and growing – challenge for society.

The aim of this research was to examine the individual and social factors that enable people to live well with dementia. The study consisted of (1) a thematic literature review and (2) primary qualitative research with professionals working in dementia care. The research focuses on the views of experts who design, commission, provide, evaluate and budget for dementia-care services. This viewpoint is informed by direct experience of working with people with dementia, and is embedded in the political economy of the health and social care sector. It represents a partial view, to be extended by future research that includes the perspectives of people living with dementia, families and carers.

The key findings that emerged from the literature and the qualitative research are outlined below.

The social model of dementia

The social model of disability (Oliver 1996) provides a holistic framework for policy and practice in dementia care. The social model of disability distinguishes between the impairment of the individual

and the disabling nature of the material, social and political environment. In contrast to the medical model, which defines disability primarily in terms of bio-medical facts about the individual, the social model sees people with a physical or cognitive impairment as also *disabled by* the barriers created by the social environment in which they live. Consequently, in addition to traditional medical support, care practices and policies based on the social model would aim to modify the external environment to remove socially constructed barriers and enable people with impairments to function well. In this research we argue that a social model of dementia provides a good foundation for planning and evaluating dementia care policy and practice.

Living well with dementia is multidimensional

Well-being is multi-dimensional and includes positive functioning in multiple domains of life. Research shows that social relationships, health and material security are particularly important aspects of well-being for people in general (e.g. OECD 2009; WHOQOL 1998).

Many aspects of life that matter to people in general remain important for people with dementia. There are some universal aspects of living well that are as important for people with dementia as they are for anyone else. However, creativity is needed to re-specify the details of living well *with dementia*. For example, while physical safety is universally important to human beings, ensuring the physical safety of a person with dementia can involve striking a delicate balance between independence and security, and requires social support of different kinds in different contexts.

This research finds that a set of interlocking ideas around social relationships, communication, personal identity and emotional well-being are central to living well with dementia.

Social relationships are the foundation of living well with dementia

> "She could end up not knowing where she is or anything, but if you could feel confident that, you know, the bus driver's going to be kind, if people around her in the shop or wherever will know her and know where to send her back to, everything changes. Instead of it feeling like a world full of dangerous strangers, if it felt like a world full of people who would help, it changes her world." (Group 2, NGO)

Social relationships are foundational to living well with dementia. This includes both the strong ties of close personal relationships that enable families to live well with dementia *together*, as well as the looser ties of wider social connection that enable a person to live well as part of a community. The quote above expresses the transformational potential of a dementia-friendly social environment. Social inclusion and involvement in everyday activities expresses respect for people's basic human dignity. This can reduce stigma, and is a central element of living well with dementia.

Care, dignity and policy

This research shows that social relationships are not only valuable in their own right, but they also underpin functioning in other important domains. For policy, this suggests that when resources are limited and practical decisions must be made between multiple valuable goals, a sensible strategy would be to prioritise support for social relationships.

The interventions and mechanisms designed to enable people to live well with dementia are as important as the target outcomes, since processes, practices and policies can be empowering or demeaning. Supporting well-being through policies and processes based on respect for human dignity is *enabling* instead of *disabling*. Some general principles that emerged include:

Support for carers

Supporting carers' capacity to care is a necessary part of enabling people to live well with dementia. This applies to both family carers and paid carers, in the community and in residential homes.

Person-centredness

As one participant put it, "Everyone wants to know what's the best thing to do for people with dementia; and actually what you need to know is, what's the best thing to do for that individual with dementia?" Finding ways to accommodate and celebrate the uniqueness of each person with dementia in terms of their needs, capabilities, preferences, identity and values is a key challenge.

Measuring what matters

In the monitoring and evaluation of services, designing ways of capturing 'softer' outcomes relating to social and emotional well-being can help to shape those services in ways that are respectful of the dignity of people with dementia and the people who care for them.

Raising pro-active awareness

"Pro-active awareness" (awareness plus strategies for action) at all levels of society – from individuals to institutions – is an important enabler of living well with dementia. This can be fostered through popular culture, the arts, and by working directly with children, organisations and individuals.

Conclusion

This research examined policy and practitioner perspectives on what it means to 'live well with dementia'. It finds that living well with dementia involves positive functioning in multiple domains of life, and that social relationships – both the close ties of personal relationships and the looser ties of wider social inclusion – are at the heart of well-being. In conclusion, the idea of 'living well with dementia' applies not just to the individuals and families who are directly affected, but also applies more broadly to how we, as a society, live well with dementia together.

Dementia, Vulnerability and Well-being: Living Well with Dementia Together

Introduction

There are an estimated 47.5 million people worldwide with dementia (World Health Organization 2015), and this number is expected to approximately double every 20 years (Alzheimer's Disease International 2015). In the UK, the number of people living with dementia is predicted to rise from 850,000 in 2015 to one million in 2025 (Department of Health, 2015), and in 2015 there are some 700,000 family carers who look after people with dementia (Alzheimer's Society 2015). In the context of an ageing population, supporting the well-being of people with dementia represents a central – and growing – challenge for society.

The National Dementia Strategy (Department of Health 2009) sets out the aim that "All people with dementia and their carers should live well with dementia." The aim of this research is to examine what it means to 'live well with dementia', and to further our understanding of the social factors that enable people to live well with dementia.

There are different ways of understanding dementia and, therefore, different perspectives on what it means to live well with dementia. While some focus on dementia primarily as a medical condition (e.g. Qizilbash et al 2015), others try to understand how dementia affects people as social beings, as they strive to live their lives alongside their families, friends and communities (Oliver 1986). For some, living well with dementia means feeling safe and secure, or feeling happy; others focus on people's capabilities to achieve a range of valuable outcomes. This report presents a review of these different approaches and perspectives, and ultimately argues for what we call a 'social pluralist' understanding of living well with dementia. This recognises that, while different people have different personal conceptions of a good life, there are some common, 'universal goods' that are part of all these conceptions. Discovering the content of this universal core of living well with dementia was an important aim of the study.

The research consisted of two main parts: (1) a thematic literature review and (2) primary qualitative research with professionals working in dementia care. Part 1 of this report presents the findings of the literature review, focusing on how 'living well with dementia' is conceptualised. Part 2 describes the qualitative research and reports the findings, and Part 3 sets out the conclusions.

Part 1. Literature review: Living well with dementia

The first part of the research consisted of a thematic review (Hart 1998) of the academic and grey literatures (for example, research reports from non-governmental organisations). Key-word searches were conducted in the Web of Science database. Primary key-words were 'Dementia' and 'Quality of Life' or 'Well-being', with further literature identified using a snowballing procedure. Only English-language literature was included, and no publication date filters were applied. A total of 131 references were identified, 36 of which were reviewed in full. Inclusion in the final review was based on assessment of titles and abstracts or executive summaries. Items were excluded if the primary focus was not well-being or quality of life.

Background

Dementia is defined by the World Health Organisation as "a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities" (WHO 2013). Symptoms typically involve

> "a progressive deterioration in cognitive function, resulting eventually in severe cognitive impairment. The individual with dementia experiences a gradual decline in their ability to understand, remember, reason, communicate and use learned skills" (Alzheimer's Society 2010).

Due to the nature of the symptoms, people with dementia are among the most vulnerable people in society. Many people with dementia are older and have co-occurring physical impairments, which may compound the effects of cognitive impairment. Dementia is also a stigmatised condition, and social exclusion is a widely reported side-effect of a dementia diagnosis (e.g. Bartlett and O'Connor 2007, Burgener et al 2015, Donovan 2012). The 2012 World Alzheimer's Report (Alzheimer's Disease International 2012) revealed that three quarters of people with dementia believed that there are negative attitudes associated with dementia in their country, and 40% reported having been excluded from everyday life, avoided or treated differently due to their illness. There are also negative correlations between quality of life and socio-economic status for people with dementia (e.g. Basta et al 2007, Rait et al 2010), partly due to inequalities in access to healthcare, material and social resources, and education. In 2010, the UN established a working group on ageing, to address the gaps in existing human rights standards in relation to older people, and because

> "Throughout the world, large numbers of older persons face challenges such as discrimination, poverty and abuse that severely restrict their human rights and their contribution to society" (UN 2012).

This observation is likely to be especially true for older people with dementia, since cognitive impairment represents an additional 'layer of vulnerability' (Luna 2014). Justice requires that social policy improve the lives of the disadvantaged and vulnerable. Dementia is a source of disadvantage and vulnerability. Enabling all people to live well with dementia is therefore an urgent matter of social justice.

The remainder of Part 1 sets out a conceptual framework for thinking about dementia (1.1), then presents the major themes that emerged from the literature on well-being and dementia (1.2).

1.1. The social model of dementia

There are two main ways in which disabilities, including dementia, can be understood: the medical model and the social model. Disabilities were traditionally defined principally in terms of bio-medical facts about the individual. On this 'medical model', the difficulties experienced by a person are due to primarily or solely to the individual's physical or cognitive condition.

The social model of disability (UPIAS 1976; Oliver 1986, 1996) re-defined disability by distinguishing between an impairment as a feature of the individual, and the disabling nature of the material and social environment. On this definition, an individual with an impairment is also *disabled by* the barriers created by their material and social environment. Consequently, in addition to individual-level medical care, policies and practices based on a social model of disability would aim to alter the external environment to remove socially constructed barriers, and enable people with impairments to function as well as possible. This definition sees disability as resulting from a combination of the difficulties that people face in their daily lives as a direct result of individual-level functional limitations (both physical and cognitive), and features of the social environment (Crow 2010; Hughes and Paterson 1997).

The social model is a useful tool for thinking about ageing and dementia. It is akin to the 'person-environment fit model' used by the World Health Organisation in their World Report on Ageing and Health (WHO 2015), and many researchers have argued that dementia is best understood in its social context (e.g. Harding and Palfrey 1997; Kitwood and Bredin 1992; Robinson et al 2011; Ward et al 2012; Whitehouse 2013). This project adopts a social model of dementia to examine policy and practitioner perspectives on living well with dementia.

1.2. Themes of well-being in dementia

Three major themes were identified in the literature on living well with dementia: (1) Contentedness; (2) Safety-Security; and (3) Social Flourishing. The three themes overlap in various ways (see Part 2), but there are important differences in the way they are defined. The first two are uni-dimensional, since both focus on a single specific domain - psychological well-being and physical security respectively.

The definition of Social Flourishing is multi-dimensional, in the sense that it defines well-being as positive functioning in a plurality of domains, including, but not limited to, psychological well-being and safety. Each theme is set out in more detail below.

Contentedness

The *Contentedness* definition of living well with dementia focuses on the subjective experience of the individual with dementia, and emphasises positive psychological states. For example, the Contented Dementia Trust (see James 2008) advocates a method that prioritises subjective contentedness in people with dementia; the most important goal is that a person with dementia feels content. Within this approach, a variety of methods and strategies are advocated to maintain the subjective contentedness of people with dementia, including techniques such as deception, which many consider unethical (e.g. Kitwood 1997; Muller-Hergl 2007; Elvish et al 2010).

Definitions of well-being and quality of life in the field of health psychology also focus on positive subjective states (e.g. Rabins and Kasper 1996; Rabins and Black 2007). While these remain focused on the single domain of subjective or psychological well-being, they tend to be multifaceted; that is, they include feelings of satisfaction in various life domains (e.g. satisfaction with health, satisfaction with social relationships), as well as global satisfaction or contentedness (e.g. Brod et al, 1999; Woods 1999; Camberg et al 1999; Trigg et al 2007; Clare et al, 2008). Notable examples of psychological definitions of well-being include Camberg et al (1999), who examine mood, affect, agitation and withdrawal; and Kitwood and Bredin (1992), who focus on 'sense of personal growth', 'sense of agency', 'confidence' and 'hope'.

An exclusive focus on subjective experience is sometimes criticised because a positive psychological state can co-exist with objective disadvantage, as people adapt and develop coping mechanisms to deal with hardship (Sen 1988). The "paradox of happiness in hardship" (Veenhoven 2005) means that subjective and objective well-being can 'come apart', and that subjective well-being is not always a reliable indicator of objective quality of life (Austin 2015). This suggests that, from a policy point of view, while people's subjective feelings about their lives are important, objective well-being should also be taken into account.

Safety-Security

The second major theme relates to the prioritisation of safety and security in the definition of 'living well with dementia' (Clarke et al 2010). Like 'contentedness' definitions, this type of definition focuses predominantly on the individual with dementia, and gives priority to a single central domain. Safety-Security definitions often tend to be more medicalised, using language around 'risk management' and 'problem behaviours' (e.g. Camberg et al 1999; Woods 1999). This kind of language and approach is

criticised by some as infantilising, suggesting a focus on "patient management" which contributes to "the bio-medicalization of dementia" (Russell 1996) and the neglect of other important aspects of life.

Social Flourishing

The National Dementia Strategy for the UK (DH 2009) exemplifies a multidimensional model of living with dementia that includes a plurality of domains, and both individual and social factors. The aim of the strategy is to set out a framework of objectives for the achievement of a society in which "all people with dementia and their carers [can] live well with dementia" (p7). The objectives recommended in the strategy recognise the joint importance of both individual and social factors in people's ability to live well with dementia. At the individual level, the importance of early and accurate diagnosis, and access to suitable treatment and information are emphasised. At the social level, the strategy highlights community support services, advocating "structured peer support and learning networks", as well as emphasising the need to raise "awareness and understanding", in order to reduce the social exclusion, stigma and discrimination associated with dementia.

An important example of a Social Flourishing approach to dementia is the Alzheimer's Society's *Dementia Friendly Communities* programme (Alzheimer's Society 2013), which works to involve people with dementia and all members of communities to create social environments in which people can live well with dementia (Crampton et al 2012). This approach encompasses a range of strategies, from challenging stigma to practical support such as befriending schemes and the creation of reliable transport options. These strategies are grounded in a social definition of living well with dementia.

Multi-dimensional well-being

It is argued consistently in the literature that a multidimensional, social definition of living well with dementia should contain disease-specific elements in order to be sensitive to the particular challenges faced by people living with dementia (e.g. Alzheimer's Society 2010, Banerjee et al 2009; Brod et al 1999; Ettema et al 2005; Rabins and Black 2007; Ready and Ott 2003). On the other hand, however, many of the domains of well-being that are important to people in general remain important for people with dementia; therefore, definitions of well-being should avoid being overly health-focused (Trigg et al 2007; McCormack and McCance 2011; Coast et al 2014).

The capabilities approach (Sen 1985; Nussbaum 2000) is an example of a Social Flourishing definition of well-being. The capabilities approach (CA) focuses not just on how people feel, but on what they are actually able to be and do in their lives. It is a broad conceptual framework that can be tailored to specific populations and contexts, and has been used in ageing research (e.g. Grewal et al 2006; Coast et al 2008; Stephens et al, 2015).

In the capabilities approach, well-being is characterised in terms of capabilities to achieve central human functionings. Functionings are a matter of what people are able to be and do (Sen 1999). Typical functionings might include being healthy, being in control of one's own life, being mobile, having good social relationships, participating in a community and having self-respect. Capabilities refer to the freedoms and opportunities individuals have to achieve these valuable states and activities. A central claim of the capabilities approach is that capabilities and functionings, rather than resources, should provide the measure of well-being. This is because the same resources can result in very different outcomes. For example, the resources a person with a physical impairment will require to achieve mobility will be greater than that of an able-bodied person. Personal, social and environmental factors all affect how resources convert into living well (Sen, 2009, ch.12; Lindley et al, 2011). Personal physical impairments, social norms, relationships and structures, and the physical layout of the built environment all affect the extent to which resources enable a person to live well. In highlighting these social and environmental 'conversion factors', the capabilities approach converges with the social model of disability (cf. Burchardt, 2004).

Although the capabilities approach was designed originally as a general theoretical approach, Nussbaum (2000) extends the theory with a list of ten central 'Human Functional Capabilities', labelled Life; Bodily Health; Bodily Integrity; Senses, Imagination and Thought; Emotions; Practical Reason; Affiliation; Other Species; Play and Control over one's Environment. Well-being in these ten central domains is characterised as dependent on features of the individual and the external social and political environment.

The central capabilities are proposed by Nussbaum as a universal core of well-being, and a set of political entitlements that a just society must guarantee to all its citizens. The list provides a framework of comparison, and will be used below to consider different definitions of living well with dementia, and to frame the findings of the empirical research (Part 2). In particular, Nussbaum's list will be used to evaluate whether there is a universal core of living well with dementia that is common across different definitions and approaches, and that should be a central part of ethical and effective policy and service provision.

Conceptions of living well with dementia

Box 1 below shows a selection of frameworks from the dementia research literature for evaluating well-being or quality of life. These frameworks were designed primarily as measurement instruments for *assessing* quality of life in dementia. However, each framework is rooted in a substantive theoretical or empirical definition of what constitutes a good life with dementia. It is these underlying theories of well-being that are the main focus of the analysis below.

Box 1: Frameworks of Well-being in Dementia	
'My Name is not Dementia' (Alzheimer's Society 2010)	**Dementia Quality of Life (DEMQOL)** (Smith et al 2005)
1. Relationships or someone to talk to 2. Environment 3. Physical health 4. Sense of humour 5. Independence 6. Ability to communicate 7. Sense of personal identity 8. Ability or opportunity to engage in activities 9. Ability to practise faith or religion 10. Experience of stigma	1. Daily activities and looking after yourself 2. Health and well-being 3. Cognitive functioning 4. Social relationships 5. Self-concept
Dementia Quality of Life (DQOL) (Brod et al 1999)	**Bath Assessment of Quality of Life in Dementia** (Trigg et al 2007)
1. Physical Functioning 2. Daily Activities 3. Discretionary Activities 4. Mobility: Ability to travel out of the house 5. Social Interaction: Social relationships 6. Interaction Capacity: Ability to interact with the environment 7. Bodily Well-Being: Symptoms and bodily states reflecting physical comfort, discomfort 8. Sense of Well-Being: Positive and negative emotional/affective states and perceptions of self 9. Sense of Aesthetics: Sensory awareness 10. Overall Perceptions: Summary ratings and evaluations about one's health and overall life situation	How satisfied are you with: • your health? • your ability to look after yourself? • your level of energy? • your enthusiasm for doing things? • the way you usually spend your day? • your level of independence? • your personal relationships? • your ability to talk to other people? To what extent are you able to: • move around your local community? • do all the activities that you want to? • do things that you enjoy? To what extent do you feel: • you have the choice to do the things that you want to do? • useful? • happy?
Dementia Care Mapping (DCM) (see Brooker 2005)	**ICECAP-O** (Investigating Choice Experiments for Older People Capability Index for Older Adults) (Coast et al 2008)
1. Demonstrating assertiveness 2. Bodily relaxation 3. Sensitivity to the needs of others 4. Humour 5. Creative self-expression 6. Showing pleasure 7. Helpfulness 8. Initiating social contact 9. Showing affection 10. Signs of self-respect 11. Expression of a range of emotions	1. Attachment (love and friendship) 2. Security (thinking about the future without concern) 3. Role (doing things that make you feel valued) 4. Enjoyment (enjoyment and pleasure) 5. Control (independence) Note: Although the ICECAP-O was not designed specifically for dementia, it has been used in a dementia context (e.g. Jones 2013).

These frameworks were developed using a variety of methods, including primary research with people with dementia; for example, the Alzheimer's Society list was developed from a literature review, plus interviews and a survey of people with dementia. The frameworks differ in their approaches to measurement. In the case of the DCM, an observer evaluates the person with dementia, whereas the BASQID uses self-reports from the person themselves. There are advantages and disadvantages to both approaches (third party versus self-reported measures), and the use of both together is often advocated (Trigg et al 2007). The literature suggests that people with mild to moderate dementia can be reliable sources of information about their own well-being (Brod et al 1999).

It is notable that social relationships appear in every framework: this provides supporting evidence about the centrality of the social in living well with dementia. Other frequently appearing elements are emotional or psychological well-being and bodily health. Interaction with the external environment is an important element (e.g. ability to 'move around your community' in the BASQID), and personal independence and control (e.g. the DEMQOL's 'Daily activities and looking after yourself') also appear consistently across the frameworks. Some of the constructs are relational (e.g. 'Sensitivity to the needs of others' in the DCM), while others are framed in more individual terms (e.g. 'Sensory awareness' in the DQOL).

Many of the elements in these frameworks map onto Nussbaum's list of universally valuable capabilities; Nussbaum's *Affiliation*; *Bodily Health*; *Emotions; Senses, Imagination and Thought;* and *Control over the Environment* are well represented. However, the frameworks both expand and refine these concepts by tailoring them to people with dementia. For example, the Alzheimer's Society list specifies 'Sense of humour', 'Ability to communicate' and 'Experience of stigma' as separate elements (Alzheimer's Society 2010). Considerations about cognitive functioning and self-concept (or personal identity) also feature more prominently in the dementia-specific lists.

Consideration of these different conceptualisations of well-being in dementia supports the two key ideas that (1) well-being is multi-dimensional and (2) there is a set of domains that are universally important to all people, and do not become irrelevant when a person has dementia – these include social relationships, emotional well-being, and ideas around independence and control. At the same time, it also suggests that, within this universal framework, additional dementia-specific detail is required, and the universal domains of well-being must be expanded or re-specified in accordance with the particular challenges faced by people with dementia.

The next section reports the qualitative fieldwork with policy-makers and practitioners. The aim of the empirical research was to build on the literature review, and increase our depth of understanding about the existence and content of a universal core of well-being in dementia.

Part 2. Living well with dementia: The professional view

The aim of the empirical work was to gather expert evidence about living well with dementia. Fieldwork with professionals working in dementia care took place in Manchester, UK, in July 2015. Participants were recruited through the Manchester Institute for Collaborative Research on Ageing (MICRA) network of over 1,200 policy-makers, practitioners, academics and members of the public in the UK. An invitation was emailed to a subset of the network, selected on the basis of their job title and organisation, and their role as decision-makers or practitioners in the field of dementia care (see Appendix 1 for details). Fieldwork consisted of two discussion groups and two telephone interviews, involving 15 participants in total. These came from three local authorities (city and metropolitan borough councils); two national NGOs; two private sector care providers; a community group; and two social enterprises. Between them, participants represented both commissioners and providers of services designed to support the well-being of people living with dementia.

With such a small number of participants it is impossible to make broad generalisations. However, the goal of the study was to gain rich insight into professional views on living well with dementia, and to lay the groundwork for future research. It is important to note that this research represents only a partial view of 'living well with dementia', from the perspective of those who design, commission, provide and budget for dementia services. Although only partial, these professional views nevertheless provide a valuable perspective – one that is embedded not only in direct experience of working with people with dementia, but also in the political economy of the health and social care sector.

Discussions were structured around two main questions: (1) What does it mean to 'live well with dementia'? and (2) How can this be achieved? These two questions relate to two main aims of the study: (1) to identify the most important, universal aspects of living well with dementia and (2) to focus not only on the outcomes (the ends), but on the processes and mechanisms (the means) of living well with dementia.

2.1 What does it mean to live well with dementia?

The three themes of living well with dementia identified in the literature (see Part 1) were introduced at the start of each discussion: (1) Safety-Security; (2) Contentedness; and (3) Social Flourishing. The Alzheimer's Society list (Box 1 above) of important constituents of a good life with dementia was also used as a discussion prompt. The Alzheimer's Society list was developed through research with people with dementia; therefore, using this as a starting point for the discussion meant that the perspectives of people with dementia were central to the discussion.

The sections below present the results of the fieldwork. The analysis uses Nussbaum's (2000) list of Central Human Functional Capabilities as a thematic framework (see Appendix 2 for details). This list is argued by Nussbaum to represent a set of universal political entitlements that every person deserves. As such it provides a useful starting point as a framework for analysing dementia as a matter of social justice.

The list is specified at an abstract level; the analysis below aims to expand and refine the central capabilities in relation to people with dementia. It is notable that every domain on Nussbaum's list was covered during the discussions, despite not being explicitly introduced to participants. This lends some support to the claim that these domains are of universal importance to human beings.

Given the theoretical importance of social connection (Nussbaum's 'Affiliation') in the social model of dementia, this domain is analysed first. Following Affiliation are the domains of 'Emotions', 'Life', 'Bodily Health', 'Bodily Integrity', 'Control over the Environment', 'Practical Reason', 'Senses, Imagination and Thought', 'Other Species', and 'Play'.

Affiliation ('Being able to live with and towards others')

The domain of affiliation includes both social connectedness in general, plus 'the social bases of self-respect' (Nussbaum 2000), which refers to recognition by society of each individual's personhood and dignity. It is notable that Dignity is one of the features that the UN (2012) has emphasised as a human right in old age.

There was consensus on the fundamental role of affiliation in the lives of people living with dementia:

> "I think that relationships and social connections is the one that probably stands out for me as well, I just think that it's got a lot of different levels in terms of getting that cognitive stimulation. And that feeling of remaining connected to other people, for a lot of people it can be quite grounding, and that process of engaging someone face to face can be very soothing and sort of can bring a person back to feeling a bit more grounded." (Group 2, NGO)

Social connectedness

In relation to social connectedness, both close personal relationships and the looser ties of wider social affiliation emerged as important. Participants agreed that close relationships with families and friends, and especially with family carers, constitute a central part of living well with dementia. Discussions were often framed by participants within a social definition of well-being, focusing on the shared needs and goals and the joint challenges of people with dementia and their families.

"I think anybody with dementia, you know, it's a completely interdependent scenario with their carer, I don't think you can ever get away from the fact that, particularly if you've got a carer who's a partner, they're particularly integrated in that person's life. Carers need as much support as the person with dementia does. And, you know, in terms of the policy decisions, I think we often don't appreciate that we can't just look at the person with dementia." (Group 2, Local Authority)

"There aren't many partner family carers who - when the person with dementia isn't with them - who've not said to me that they're really struggling with depression. They're exhausted, they've got issues with sleep, and it's that - who's caring for me? They're just like, they're going all out, I'm going to look after you, and they're not getting any re-charge." (Group 1, Social Enterprise)

These quotes demonstrate that people with dementia and family carers have both specific individual needs, and many shared needs and goals relating to the capability to *live well together*. The quotes highlight the vital role of support for family carers, in terms of their own individual needs and goals, as well as shared needs and goals, including their capability to care for the person with dementia.

It was observed by participants that there are often many complex emotions to be dealt with: carers and close relatives may experience feelings of loneliness, anxiety and sadness, as well as "a cocktail of guilt, bitterness; all those kinds of things" (Group 1, Community Worker).

"If that person is very aggressive, or brings up very difficult things from the past, and you're a family member, it's not an easy time for relationships at all. It's all very well to embrace that reality if it's all about the fun things, or even just the chit chat about anything, but when it's something quite emotional or quite difficult…" (Group 1, Community Worker)

The emotional well-being of family carers and relatives may also be affected by feelings of embarrassment, shame or stigma:

"[There's] a man who comes in with his wife who has dementia, and he tends to be very apologetic, you know, 'Sorry about my wife, she's got dementia'" (Group 1, Local Authority, Creative Arts)

A common challenge for people in living well with dementia together is adjusting to changes in roles and relationships. Family members often experience a sense of loss if their loved one begins to change, and participants highlighted the tension that can arise between family members' desire to stay

connected with the 'former' person, and the need of the person with dementia to live and be as they are now, perhaps mainly "in the moment".

The desire of family carers and other family members to try to 'hold on' to what the person with dementia used to be may reflect changing identities and roles – for example, between marital partners, and between parents and children. For instance, an older man who takes on a care-giving role, perhaps for the first time in his life, may find it difficult to adjust to this new identity. The desire to 'get the old person back' may also be related to the every-day difficulties of living with or caring for someone with dementia:

> "It's very difficult for the wife to live with somebody who says 'you're not my wife'. And when I'm talking to someone, I explain, you know, 'wife' is just a label, it's just a word that someone's forgotten…they feel that this man or this woman is now a stranger, because they've denied I'm their husband or wife […]. And of course if they've been married so long, so many habits that have become part of their relationship, and if that's gone…" (Group 2, Community Worker)

Changes in these social identities can be challenging on practical grounds, as well as on grounds of the emotional well-being and self-identities of friends, relatives and carers.

> "That different relationship with children, especially if their husband or wife has died, it's a really complex one - how you interact with your child, male or female, and the differences… different expectations; different levels of patience!" (Group 1, NGO)

This shows that it is not only the person with dementia whose self-identity may be fragile and in need of support, but that support for the personal and social identities of carers, and the inter-relationships between people, is required for living well with dementia together.

The value of social contact more generally was also highlighted by participants. Discussing social visits to people with dementia, participants observed that people are usually "just delighted to have someone to talk to and listen to them" (Group 1, Community Worker), and that regular social contact can have wider benefits, for example on people's communication and cognitive skills:

> "It's like people who live on their own and they go and stay with their families for a week or two, and the families say 'gosh, by the end of the holiday it was like they were back to normal', so I think it's just having that constant social stimulation." (Group 2, NGO)

Loneliness was highlighted as an important barrier to living well with dementia, especially when old relationships break down:

> "The statistics about how people lose their friends after diagnosis, and you hear those stories about how that does actually happen and what a massive impact that has on people in so many different ways." (Group 2, NGO)

Loneliness can be particularly a problem for people living on their own, but also for those living with family or in care homes; one participant pointed out that it is possible to be "lonely in a crowd".

Many of the symptoms of dementia, such as memory and concentration difficulties and problems with verbal communication, are likely to have direct impacts on people's capability for affiliation. Participants suggested that this leads to a need to rethink how the concept of 'relationship' is defined in the context of dementia:

> "It depends how you're going to define relationships, doesn't it. If you're thinking you've got to have lots of good friends around you, it doesn't have to be that." (Group 2, Local Authority)

> "The meaning of 'relationships' changes, they become more episodic than continuous. A volunteer who comes and holds your hand can provide comfort in the moment, but no long term relationship may develop." (Telephone, NGO)

> "I've been going in looking after one lady at lunchtimes once a week, and after six weeks she still can't remember my name. But she knows me, so now that's a relationship, and it might not be a relationship in the way I used to think about it, but it is." (Group 1, Community Worker)

As the second quote above suggests, for people with advanced dementia, the immediate experiential aspects of social interactions may be of increased importance, while the discursive and deliberative aspects may become less available. Therefore, creative approaches that enable people to communicate and express themselves are another way of supporting affiliation:

> "It's through communication and interaction, you necessarily have to have a relationship with someone...what type of relationship? Being able to communicate in a way that is expressive means that you've got that almost friendship and emotional bond with whoever you're engaging with, it allows that space for relationships to develop." (Group 2, Local authority)

Examples of alternative ways of communicating with people included through sound and music, and through the use of objects to facilitate interaction, including 'reminiscence' props such as photo albums and vintage clothing, as well as other sensory objects such as artwork and toys. It was also pointed out that interaction and communication can be made much easier through simple adaptations to the physical environment – for example, by re-arranging the furniture in a care home:

> "In care homes the rooms aren't set up right. Instead of all the chairs round the edge, put four or five in little circles so people can see each other and communicate, and perhaps some objects or props on the table to facilitate conversation." (Telephone, Charity)

Again, participants stressed the much wider benefits on other domains of life of affiliation and communication. In a discussion about creative arts projects with people with dementia, one participant reported:

> "… enabling them to communicate and express themselves means they don't feel the same levels of distress. And we've found amazing clinical outcomes as well as social outcomes, in people's memory tests, and other tests that have been done by clinicians, after only a few weeks of music-based creative activity […] It becomes more than, I guess, communication in a traditional sense. It's not about having a conversation like this, and saying 'I would like this, I would like that' – that decision making and human agency – it's about expressing things that they have done in the past, things that have contributed to their life, and allowing that time about what they're doing now, and how they feel and think now." (Group 2, Local Authority)

This participant disassociates communication and interaction from an 'idealized' rationality, and suggests that affiliation and meaningful self-expression are not dependent on the ability to engage in cognitive reasoning.

Participants also discussed the links between affiliation and communication in the context of facilitated relationships – for example, befriending schemes and facilitated support groups. The role of care home staff in enabling the social engagement of people with dementia was also emphasised:

> "We did communications training with everybody in one care home - the cleaners, the kitchen staff, everybody had the same training, so that everybody could engage with people in a better way […] Once people start talking, it's really helpful, you know, and sharing: 'Did you know Fred does whatever', or something like that." (Group 1, Social Enterprise)

"Even as I am completing a task [e.g. getting someone dressed], I am also having a conversation. Even if I've only got 5 minutes, I can still make it count, can't I." (Group 1, Community Worker)

These discussions show that creative social engagement and communication strategies can be beneficial for people with dementia in a number of ways, including the immediate subjective pleasure experienced, by supporting and enhancing cognitive capacity, as well as the dignity inherent in engaging with a person as a human being, and recognising and supporting their personhood and self-identity.

The social bases of self-respect

The social bases of self-respect, including "being treated as a dignified being whose worth is equal to that of others" (Nussbaum 2000), rely on structural institutional factors, as well as social factors such as the attitudes, behaviours and norms of the wider social group.

The importance of social attitudes in enabling people to live well with dementia was repeatedly stressed by participants. Stigma surrounding dementia was thought to stem from fear and misunderstanding:

"It's fear, as much as anything. Dementia is what cancer used to be." (Group 1, Local Authority)

"There is a real lack of understanding and compassion actually for people with memory problems, and it's like cancer was a long time ago - you know, nobody spoke about it." (Group 2, Local Authority)

"I think a lot of attitude is around fear, isn't it, so many people are scared of getting dementia, because it is painted as such a negative future for everyone." (Group 2, Local Authority)

The self-stigma and shame that can result from these wider social attitudes are also barriers to living well:

"You talk to people who say, you know, I'm worried about my memory, and you can try and get them to go to the GP about that, but many people would just not want to face up to it, because the way dementia is seen as such a stigma, isn't it." (Group 2, Local authority)

An important theme to emerge in relation to this was the importance of recognition, patience and understanding on the part of service workers, such as people working in shops and public transport:

> "Going to the shops and getting on a bus can be very worrying and frightening: where to get off, have I got enough money, will the driver be patient? Streets are scary places to be – the traffic, pelican crossings…" (Telephone, Charity)

> "[At the supermarket checkout] there was a lady, she obviously couldn't open her purse, and in the end the young woman at the till took the purse from her…I said to her, 'Oh, you were marvellous', and she said, 'Well that lady comes to me especially,' so she knew her." (Group 2, Community Worker)

This example highlights the importance of awareness among service workers in enabling people with dementia to access services and amenities. Participants mentioned schemes such as 'dementia friendly checkouts' in a national supermarket chain as examples of progress in this area.

The role of the general public in creating 'dementia-friendly communities' (Alzheimer's Society 2013) was strongly emphasised by participants:

> "I'm thinking of one lady in particular… she could end up not knowing where she is or anything, but if you could feel confident that, you know, that the bus driver's going to be kind, if people around her in the shop or wherever will know her and know where to send her back to, everything changes. Instead of it feeling like a world full of dangerous strangers, if it felt like a world full of people who would help, it changes her world." (Group 2, NGO)

This quote expresses the transformational potential of a dementia-friendly social environment for a person's capability to live well as part of a community; to be able to move around safely and confidently in their surroundings, and to access the public spaces and institutions of everyday life. This kind of affiliation highlights the links between social connectedness and the social bases of self-respect. It also connects with the capability for Bodily Integrity (in terms of safety and the freedom to move around), and to identity, agency and practical reason (see below).

To summarise, the findings suggest that communication is foundational to both aspects of affiliation - social connectedness and the social bases of self-respect. However, the concepts of 'relationships' and 'communication' need to be creatively modified in the context of dementia, for example, by relying more on alternative, non-verbal forms of connection. The findings also highlight that social interaction buttresses various other valuable goals, by supporting the personal identity and emotional well-being of people with dementia, and by accomplishing valuable outcomes together with others. This implies

that the capability to communicate in different ways is a central part of affiliation, and therefore a central part of living well.

Emotions

Participants discussed many elements of emotional well-being. As well as 'contentedness', other major themes that emerged were the importance of being able to show love and to *give* care, and the role of humour.

Contentedness

The concept of contentedness and subjective well-being has growing influence in public policy (Austin 2015), not least in relation to dementia-care: as discussed in Part 1, for example, the Contented Dementia Trust advocates care strategies that place ultimate priority on the subjective states of people with dementia. Participants agreed that the emotional well-being of people with dementia is very important, especially given the anxiety, fear and depression that can accompany dementia:

> "The people I see, I see many of them that are just sad, and I suppose I'd rather they were anything other than sad." (Group 1, NGO)

Some participants viewed subjective well-being as closely related to relationships with others; one participant stated that "love is at the centre" of contentedness (Group 1, Community Worker).

Participants also linked the importance of subjective well-being to the observation that people with dementia, particularly those at a more advanced stage, are living "in the moment", so their immediate affective state is especially important. This suggests that emotional well-being may take on increasing significance as other capabilities become diminished:

> "Once someone is reaching the later stages, maybe contentedness is – I'm thinking of a gentleman I saw last week who can't even hold a conversation anymore, but anything we can do to make him feel, in the moment, content, and listened to and valued, is going to be a big improvement on his current situation." (Group 1, Community Worker)

> "People - especially people with advanced dementia – are living in the moment, so contentedness is more important for them." (Telephone, Charity)

However, most participants suggested that, important though it is, contentedness must be balanced against other considerations; contentedness taken at face value was seen, overall, as "a bit narrow" (Group 2, Charity). Different types of emotion must be distinguished: while distress, fear and anxiety were seen as unambiguously negative, this is not the case for some types of discontent – for example "bolshiness" or annoyance. The manifestation of personality traits such as assertiveness or bossiness may be interpreted as an exercise of agency; similarly, angriness or annoyance may be well-justified, and may function as an important signal regarding some need or care deficit. Participants contrasted "bolshiness" with "passivity", seeing the latter in a negative light: passive contentedness cannot be taken as a sign that someone is living well with dementia, and could indicate that someone is under-stimulated or over-medicated.

During a discussion about a lady who was concerned that her husband (who had dementia) was withdrawing from the world, losing touch with friends and losing his hobbies and interests, one participant commented:

> "…the lady says he seems very content – and she used that word 'content' – to stay upstairs just watching television." (Group 2, Local Authority)

This example illustrates a case in which a family carer interpreted apparent contentedness as a sign that the person with dementia was *not* leading a full and flourishing life. Contentedness could signal a passive state of non-flourishing, and some types of discontent may be legitimate and valuable forms of expression. Overall, the value and role of contentedness in a person's life must be balanced against a wider set of considerations and values.

The capability to love and give care

Another important aspect of the capability for emotions that emerged from the discussions, and is included by Nussbaum in her characterisation of this capability, was the need to recognise people with dementia not only as recipients of care, but as people with the capacity to give care themselves.

> "There's one lady that we visit and give some companionship to, and the conceit is that we're just popping round and she's helping us, and that helps her to feel, you know, she acts as the perfect hostess, she offers tea, and we might have to help her make it, but she's offering it because it makes her feel…She was a very sociable lady, and she did help a lot of people in her community when she was younger." (Group 1, Community Worker)

> "There was a children's nursery there [at the care home] and they shared activities and they shared lunches, and there was this great footage of them just hanging out; just having lunch together, just connecting, just holding hands. And when you go in care homes you never see any children there, you just don't. So I'll quite often go in with either my baby or my dog, or sometimes both, because if you go in with those, someone's always going to connect with you." (Group 1, Social Enterprise)

These examples highlight the importance of the opportunity to *give* care in supporting people's self-identities and their capability to feel emotions such as belonging and respect; both the respect of others and self-respect. They also show how the opportunity to give care or to express caring attitudes (e.g. towards a baby) can be a form of mediation for social connection.

Humour

A final aspect of emotional well-being that came up during the groups was humour – "having a laugh and a joke" (Group 1, Social Enterprise). It is notable that Sense of Humour also appears on the Alzheimer's Society list of aspects of a good quality of life (see section 1.2). The importance of this emotion and its associated behaviours may lie in the social and relational aspects of having a laugh and a joke, as well as the role of humour in creating a sense of normality, and connecting with a person on a distinctly human level.

In summary, the discussions around emotions suggest that many important aspects of emotional well-being are relational (e.g. being able to love and care for others, sharing humour), as well as individual (e.g. feeling content, having peace of mind). Positive emotional functioning is contingent on social relationships: *Emotions* and *Affiliation* are closely inter-related.

There are, of course, many difficult emotions that are often faced by people with dementia and their families and carers. Aggression, for example, was seen by participants to be related often to fear or pain. Feelings of anxiety, depression and loneliness may be experienced by families and carers as well as people with dementia. Participants agreed unequivocally that living well with dementia depends on finding ways to minimise these types of emotion.

Life and *Bodily Health*

The functional capability for 'Life' is defined as "Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living." 'Bodily Health' includes being adequately nourished and sheltered" (Nussbaum 2000:79).

Dementia is a life-shortening condition, and the majority of people with dementia are older and often have complex health needs. The evidence also shows that older people in general are more likely to live in fuel poverty (Age UK 2014) and have lower ability to buy nutritious food due to budgetary constraints and mobility issues (Dowler and O'Connor 2012). Physical health is a central part of living well with dementia, and so considerations around food and energy insecurity are relevant here.

Despite the many challenges faced by people with dementia, participants agreed that a life "worth living" with dementia is certainly possible. Access to suitable health and social care is clearly foundational for life and bodily health for people with dementia, as it is for all older people and all people in general. An important theme that emerged related to awareness and understanding among doctors and nurses in the primary care and hospital sectors:

> "In hospital, making sure the staff are aware that the person has dementia and they won't remember their glass of water, you've got to sit with them." (Group 2, NGO)

> "GPs should do it [Dementia Friends training]." (Group 1, Social Enterprise)

> "That's a good idea! Well I struggle to get doctors to come and do Dementia Friends training because they're so busy." (Group 1, Community worker)

The active awareness of medical staff of the vulnerabilities of people with different types and at different stages of dementia is important in the domain of health, especially since people with dementia may, more than others, have diminished ability to communicate and self-advocate. Being free from pain was considered by participants to be "basic", and it was observed that aggressive behaviour is sometimes due to bodily discomfort.

A further consideration relating to health was the ways in which people with dementia can be supported to do physical activity:

> "There's one activity called Circle Dancing for Dementia, and it's especially good in care homes…as soon as the music starts people start moving…so they get some exercise, but the word 'exercise' is banned because that puts everybody off!" (Group 2, Charity)

This example showcases a sensitive approach to supporting the bodily health of people with dementia which also highlights the importance of social relationships, since the activity is facilitated by others and performed as a group.

Bodily integrity

'Bodily integrity' is defined in relation to safety and security, and being able to move around freely (Nussbaum 2000:79). The safety and security of people with dementia was considered by most participants to be fundamental to well-being, in the sense of being a 'basic need' (Doyle and Gough 1991), upon which the ability to live well in other areas rests.

> "The safety-security to me is your foundation. If you've not got that, you've not got anything else. You've got to have that, but that's not a happy life, that's just being safe and secure."
> (Group 1, Local Authority)

The fundamental importance of safety and security was, however, subject to two important qualifications. First, participants considered it to be universally important among human beings, not just people with dementia. There may be specific considerations to take into account for different people in different situations (e.g. people with different types and stages of dementia, who are living in the community or in residential care), but this is no less true of the general population and other particular vulnerable subsections of it.

> "Like any person, I don't think any of us would think we were living well if we were experiencing any kind of abuse or if we were at risk of being harmed and didn't feel safe…in the same way as you keep anybody safe from harm, and anybody secure. I feel to apply another layer of that to people with memory or cognitive problems, feels oppressive."
> (Group 2, Local Authority)

Second, it was strongly emphasised by various participants that too much focus on safety and security can be "restrictive" and might lead to an imbalance with other important domains.

> "There is a lot of focus on safety and security, I think at the expense of people being able to take normal risks that everybody takes every day." (Group 1, NGO)

> "We're seeing people who are very safe and very secure, but at what cost? They're missing that social flourishing, they're missing those community connections, they're missing life!" (Group 1, Social Enterprise)

Participants also highlighted that the safety-security issue can be an area of contention or mismatch between the priorities and needs of care-givers and people with dementia, with safety and security

sometimes being a higher priority for family members and care-givers than for the person with dementia themselves.

However, while participants agreed that a diagnosis of dementia, on its own, is not sufficient to restrict a person's freedom in the name of safety, some highlighted the complexities for decision makers in striking the right balance between autonomy and independence for people on one hand, and safety and security on the other:

> "…you're not going to get providers taking risks, because it's not that climate, and actually we'd probably come down on them like a ton of bricks if they did, and somebody got out and was found walking down the motorway, which happens a lot, so I think we have to be realistic as well about what we can achieve." (Group 1, Local Authority Commissioner)

This highlights the tension between protecting the bodily integrity of people with dementia and enabling freedom and self-determination. It also suggests that institutionalised risk management might sometimes impede individuals' ability to live independently.

> "…having seen it [a care home] from the outside I thought it was going to be amazing, but actually it was like a prison - a very, very plush prison […]. Honestly, I'd do anything to avoid someone going into it, I'd rather they died on a motorway because at least they'd have done so with that feeling of freedom." (Group 1, Community Group)

These examples show that a balance must be struck between protecting people against harm, whilst enabling autonomy within this framework of protection. For example, while someone with advanced dementia may not be able to leave a care home unaccompanied for reasons of their bodily safety, a well-designed care home environment and opportunities for accompanied outings can enable people to have some freedom of movement:

> "Ideally, a care home – very few of them do – a care home has an outside space that people can go into safely." (Group 1, Local Authority Commissioner)

> "We do try to organise them [visits to a gallery] because people say that it's - they just really enjoy getting out of the space, and their reaction is often about the trip into town. It could be tea and a cake; the whole experience." (Group 1, Local Authority)

This second quote also hints at the importance of general social inclusion, and the value for people with dementia of life 'beyond dementia', away from care homes and dementia-specific activities. This theme is discussed further in relation to *Play*, below.

The issue of making sure that people with dementia are safe from people who might take advantage of them also arose. However, this again poses the question of how much more protection people with dementia need, compared to other older people and to other vulnerable groups. Overall, it may be necessary to say that, while the need to find a balance between security and freedom is a universal constituent of the capability for bodily integrity, exactly where the balance lies must be addressed on a case by case basis, in response to the specific attributes and vulnerabilities of particular people in particular environments.

Control over one's environment

Control over the environment includes both the physical, material environment and the political environment (Nussbaum 2000). Control over the physical environment may refer to the relatively limited environs of a residential care home, or to private homes and the wider community. For people living in the community, control over their environment depends on a great number of actors and agencies, including every-day institutions such as shops and medical centres (and the people who work in them) and the wider public, as well as the built environment itself.

The role of assistive technologies, including 'telecare' or remote monitoring, was mentioned by some participants as an increasingly important feature of home environments that can enhance people's confidence and control, especially people who live alone (see Robinson et al 2009). Beyond private homes, the priority of making public spaces easy to navigate and use, for instance through clear signage and lots of places to sit down, was highlighted as an important enabler of this capability:

> "[We need] universal public spaces to be welcoming, you know, the physical environment or the building to be designed in a way which means that somebody with dementia could get around - it's not confusing, there aren't too many falls risks, you know, all the walls don't look the same so you don't know which corridor you're in." (Group 2, Local Authority)

One participant noted that many dementia-relevant aspects of the design of public spaces and the built environment are equally applicable in people's homes. For example, the need for plenty of natural light to help people with poor eyesight, and avoiding certain materials; for example, shiny floor coverings may be slippery and can be mistaken for water. The literature also emphasises the importance of the

design of the built environment in enabling people with dementia to function well both at home and away from home (e.g. Rosenberg et al 2012; Clarke and George 2005).

Another aspect of control over one's environment relates to material security and control over one's financial affairs.[3] People with cognitive impairments may have diminished ability to make financial decisions, and may be vulnerable to fraud or financial manipulation. The concept of guardianship (including, for example, Lasting Power of Attorney) seems relevant here. Although there may be some risks (one participant spoke about experiences of family members taking money illegitimately from relatives with dementia), this is another area in which the capability for control over one's material environment depends on the support of others.

One aspect of control over the political environment is participation in decisions that affect everyday life. Given that people with dementia have greater dependence on others in achieving many important things in life, it seems especially important that there should be mechanisms to enable them to be involved as much as possible in decision making. This might range from including people in decisions about what to wear each day, to advance care directives that enable people to have greater input into how they wish to be cared for in the future. In a care home setting, it may also be possible for some people with dementia to be involved in decision making processes at higher levels, for example, in the evaluation of services (Cheston et al 2000).

Finally, with respect to people living in residential homes, as participants highlighted in discussions about the Safety-Security theme, care homes can be more or less conducive to residents having control over their environment. As one participant put it, "There are other ways [of keeping people safe] without essentially locking someone up" (Group 1, Community Worker).

Practical reason *('Critical reflection about the planning of one's life').*

Practical reasoning, along with the related concepts of agency and self-identity, is one of the most difficult and controversial areas of dementia care (Firlik 1991; Dworkin 1993; Dresser 1995; Jaworska 1999). By definition, dementia involves at least some diminishment of some of the cognitive faculties (for example, memory and, depending on the type of dementia, semantic deliberation) that are required for practical reasoning and agency as traditionally understood.

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[3] This is especially relevant in the context of the 2015 investigation by the UK Information Commissioner into telephone fundraising by charities.

Practical reason and agency

Practical reasoning – deliberating about how one wishes to live one's life – is closely related to the idea of human agency. The diminishment of the cognitive capacity for agentic decision-making is a characteristic of dementia. However, the level of mental incapacitation suffered by an individual depends on various factors, including the type and stage of dementia. Therefore, it is important that cognitive capacity is not simply assumed to be reduced or absent.

> "...the smaller decisions that sometimes get removed from people because they're deemed to not have capacity, which, I think, can be a bit sort of overused and a bit too general. You might not have capacity to make certain decisions but there are lots of things that you can still decide on." (Group 1, NGO)

> "There was this poor woman at X, and she kept saying to her family, 'There was a donkey in here.' [They said] 'Oh you know, it's just Mum', and there had been a donkey in! Someone had brought a donkey in!" (Group 1, Local Authority)

These examples reveal participants' concerns about the capacity of people with dementia sometimes being under-estimated, including by those who know them best.

A related issue arose concerning the relationship between a person with dementia as they are now, and their 'former' self.

> "I was working with one guy who used to love gardening, and wasn't able to do it anymore because of his vascular dementia and some physical limitations. So his wife was trying to do everything she could to try and get him back into it, but he'd actually already decided, right, I'm not going to be doing that any more, and moved on, almost. I definitely think that the carer will be doing everything they can to maintain what they used to like and want to do, and maybe that person has made the decision themselves that they don't want to do it." (Group 2, local authority)

This example raises many issues about agency, identity, practical reasoning and adaptation. It may be difficult or impossible to know whether changes (for example, abandoning a life-long love of gardening) are due to the progression of dementia, or to a 'normal' change in preferences as the person has aged.

> "...somebody in life will change, and somebody with dementia in life will change, and as we age, what we want and think and feel may or may not change […]. If that person, without dementia,

decided he didn't want to do gardening, the wife probably wouldn't feel such an emotional wrench that he wasn't doing the gardening [...]. It's almost like we don't allow people with dementia to change." (Group 2, Local Authority A)

This again shows concern about a perceived tendency towards the underestimation of the capacity of some people with dementia to make 'real' decisions for themselves. More generally, decision-making, agency and rationality pose difficult questions in relation to people with dementia. In response, some participants advocated a broad, non-idealised conception of 'rationality', which recognises that rationality can be expressed in various ways, including in everyday habitual action. This contrasts with the idealised conception of rationality assumed, for example, by neo-classical economists and many philosophers:

"You don't choose to be the way you are though, do you, people go about their day not really conscious of how they're acting." (Group 2, Local Authority)

Related to this, the literature contains references to 'habituated' and 'embodied' agency, and examples of these emerged in the discussions:

"...he [a care home resident with dementia] had been a headmaster, and he was saying 'your skirt is too short'!" (Group 2, Community Worker)

These discussions show that the concepts of agency and rationality need to be broadened, since the traditional definitions are inadequate in the context of dementia. Using the traditional idealized concepts of agency and rationality as benchmarks seems to lead inevitably to a 'deficit model' (Stephens et al 2015) of dementia.

The discussions also revealed a critique of an individualised definition of agency, in favour of a relational definition grounded in affiliation. For example, participants discussed the idea of 'assisted autonomy' – the idea that, with the right support, people can be enabled to make decisions and to act upon those decisions. This again entails a social definition of personhood, and understands agency and practical reasoning in the context of social relationships (cf. Jennings 2010).

In parallel with advocating a relational perspective on agency, identity and practical reasoning, participants also highlighted some tensions and risks, all relating to power imbalances between carers (including institutional, paid and family carers) and people with dementia. First, in the context of assisted autonomy, mismatches in the psycho-social needs of carers (especially partner family carers)

and the person with dementia can lead to the over-riding of the person with dementia's needs. For example, family members' desire to "pull the person back to what they were" could cause distress to the person with dementia, and may not be the best way to support that person in living well (Telephone, Charity).

The idea of assisted autonomy also raises the problem of paternalism.

> "There was one lady who only wanted to eat cream cakes. Her two daughters disagreed on what was best for her. But the lady got comfort from it…it was difficult for her to go out, and she was very firm about it. She'd been a strong lady, the leader of the family, and she was very clear about what she wanted." (Telephone, Charity)

Finding a balance between respecting a person's agency and preferences, and over-riding them out of consideration for that person's wider well-being (in this case, the lady's nutritional health), is clearly a challenge, especially for family carers, and especially if the person with dementia lacks awareness (some or all of the time) about their condition.

Identity

The question of agency is closely related to the question of personal identity. This is a particularly challenging aspect of the ethics of dementia care, especially in relation to the types of dementia that cause changes in personality and behaviour that can be alienating and difficult for carers, friends and family members – that is, for those who are most closely involved in the self- and social identities of a person with dementia. As well as being difficult for those around them, the loss of a sense of self is difficult and frightening for the person with dementia themselves, depending on their level of awareness. One participant reported a person with dementia agonising that

> "I'm losing me" (Group 2, Community Worker).

Participants tended to agree, however, that a core of self-identity remained, even during the most advanced stages of dementia:

> "I feel personally that there is something that will always remain, like, forever…I've come to that conclusion based on how people can, people do still remain responsive to interactions with other people. Even if it is really limited, there's always going to be something there." (Group 2, NGO)

This participant affirms a social definition of identity, linking self-identity to the capability for affiliation and the capacity to engage and interact with others. This quote also suggests that affiliation in some form is possible when many other outcomes are unachievable. As Lindemann (2010) notes, a person can be "held in her identity" by her family and others who know her well, through the narrative coherence that social relationships give to a person's life.

Finally, questions around self-identity in dementia are also important from a strategic, practical point of view:

> "The assumption is that people do lose their sense of selves and they are completely altered and completely changed by having dementia. And I think that means that, in some ways I think that's quite a convenient viewpoint for society at large to take, because it makes it easier to deal with the situation, and it takes away a lot of the guilt about people being in residential care and not getting enough social [interaction]. And it takes away some of the guilt that we're not caring for people as well as we could be, and I think that that attitude needs to be changed too." (Group 2, NGO)

In summary, practical reason and agency - suitably redefined in terms of non-idealized relational rationality and agency - seem to be as important for those living with dementia as it is for the wider population.

Senses, imagination, and thought

Participants gave the impression that strategies for engaging the senses and imagination, such as art and music therapies, are relatively common in dementia care, and that these experiences can be important for people in a number of different ways.

> "They might have no recognition whatever, but experiencing something kind of takes you to a place…You may not have the words, but the smells, you recognise it. You mentioned going to a gallery. I try not to do the whole thing of 'do you like art, don't you like art'. It's more about what art can trigger…if you explore a painting together, it's how you respond to that painting. We did some work recently with a day centre and nursing home, and the conversations that people had, through sounds and objects - we've got a box of objects that got people talking." (Group 2, Local Authority)

> "…someone else who doesn't speak at all, we learned she'd been a dancer and had done Can-Can in London, and things like that. And she can't even hold her head up, she has a neck brace

and everything, but she was actually singing the next note, even though she hadn't heard the music before - you know how you can anticipate what the next note is going to be in the song - because she was so musical." (Group 2, Community worker)

Experiences involving senses, imagination and thought, particularly relating to art and music, may be important because of the immediate "in the moment" experiential pleasure they can provide. As the first quote above suggests, this kind of experience need not always require semantic or cognitive engagement beyond the direct sensory experience. The example of the musical lady also shows how these experiences can connect with and reinforce self-identity; and since these experiences often take place with another person or other people, they also represent opportunities for affiliation. Therefore, although the cognitive capacity of a person with dementia may be diminished, the opportunity to participate in activities that engage 'senses, imagination and thought' can clearly contribute in various ways to living well with dementia.

Other species (*'Being able to live with concern for and in relation to … the world of nature'*)
Participants considered the ability to go outside and enjoy fresh air and sunshine to be an important part of living well with dementia. They criticised care home environments where residents "don't even go outside or they don't get fresh air, you don't see people in the garden" (Group 1, NGO), suggesting that the absence of these opportunities is a barrier to living well.

Animals can also play an important role. Whitaker (2015) discusses the HenPower project, an example of a successful project that uses hen-keeping to address loneliness and depression among care home residents with dementia. The project aim is to give residents roles and responsibilities in caring for the animals: "HenPower moves away from passive care and harnesses people's imagination and interests" (Whitaker 2015). As mentioned above, engaging with animals can provide opportunities for social affiliation, and opportunities for expressing or giving care, which can connect with and support personal-identity. Similarly, studies (e.g. Tse 2010) have shown the value of providing nursing home residents indoor plants and flowers to care for.

Play ('Being able to laugh, to play, to enjoy recreational activities)
The importance of humour has already been mentioned above in relation to *Emotions*, and people's ability to enjoy recreational activities was mentioned often by participants. This may involve participation in activities that connect with interests that a person had prior to dementia; participants mentioned dancing, gardening and singing as examples of recreational activities that, in their experience, had been 'meaningful', in the sense of meaningful to particular people with dementia:

"And stuff that has meant something to them in their life, so if they've always been interested in art, chances are they're still going to be interested in art; if they've loved gardening, that's probably still going to be there…" (Group 1, Social Enterprise)

"We did some gardening the other week, there were quite a few people with dementia who came to join in … The park staff who were working with us, they could easily identify the person who'd actually worked in the park in the past, because he was so much better at it than the rest of us! So he still retained those skills, despite his dementia." (Group 1, NGO)

This suggests that recreational activities that engage a person's interests and skills have the potential to support that person's identity and self-respect. It also connects to one of the major themes that emerged from the discussions, namely the importance of opportunities to participate in life 'beyond dementia'. Participants stressed the need for people with dementia to have opportunities to participate in 'normal' life activities. Activities designed around specific dementia-related considerations (e.g. dementia support groups) are very important, but there is a need to go beyond these:

"There has been a focus on the groups and the cafes and the group-based situations, because it can be a really powerful experience, and for some people they're great and they really are life changing, but there's a lot of people that are just, 'that's not for me'." (Group 1, NGO)

This shows how individual personality type is important in determining the advantages and disadvantages of these types of activities for any given person, and highlights that 'people with dementia' are not a homogenous group who can be provided with 'standard' activities.

More broadly, participants considered there to be great value in enabling people to take part in the wider life of a community, 'beyond dementia':

"I don't want to say 'activities', because everything's an activity, and like going to the pub shouldn't be called an activity, should it - it's just life. That's just something that we would all do on a Friday night; we go to the pub. It's not a 'Going to the pub activity'..." (Group 1, Social Enterprise)

"There's a gentleman who's in his late 90s. When I met him he just wanted to show me all the paintings he'd done after he'd retired. There was a course going on at the time, 'Painting for Health', which is a mixed group of people. As soon as we went into the studio which is in an old mill in the middle of X, you could tell it wasn't a day centre, it wasn't anything for usual bingo

and that kind of activity. And he picked up a brush and it's changed his personality! He's now developed a sense of humour! I mean there he is, in his 90s, and he's developed a sense of humour!" (Group 2, Community Worker)

Supporting social inclusion and involvement in life 'beyond dementia' expresses respect for people's basic human dignity, by not defining them solely by their impairment. This reduces stigma and therefore enhances self-respect and self-identity. At the same time, the importance of dementia-specific activities for many people is clear. This suggests the need for a balance between the complementary ideas of (1) supporting the wider social inclusion of people with dementia, and (2) enabling people with dementia and their families to engage with others in similar situations, which may also be stigma-reducing, and an important source of emotional and practical support.

Summary: Living well with dementia (the ends)

Overall, there was consensus among participants that living well with dementia is multi-dimensional – it includes, but goes beyond, simply feeling content or being safe. There was also agreement across the groups and interviews (and in the literature) that a definition of living well must be specific to people with dementia, but not completely dementia-focused. This is because there are universal aspects of well-being that apply to all human beings, with or without dementia. At the same time, these universal human aspects must be carefully tailored to people with dementia as a group, as well as to particular individuals. Affiliation was singled out as especially important, both in its own right, and because it supports positive, secure functioning in so many other domains.

Section 2.1 has set out participants' views on the content of 'living well with dementia'. The next section turns to the means of achieving these outcomes through policy.

2.2 Processes and Mechanisms: The Means of Living Well

A definition of living well with dementia should include not only well-being outcomes (the *ends*), but also the *means* by which good lives are achieved. An example given by a participant provides a simple illustration of this principle: in order to protect the bodily integrity – the safety – of a person with dementia, that person could be "essentially locked up" (see section 2.1), or alternative means of achieving the same outcome could be found; means that do not demean and unnecessarily restrict the person.

Social Flourishing

Participants agreed that multi-dimensional social flourishing should certainly be the main aim for people with mild or moderate dementia. However, there were some differences in opinion around the

balance between pragmatism and aspiration in the case of those with advanced dementia. On one hand, some participants saw social flourishing as an ideal, but one that "might be too big a goal" (Group 2, Community worker):

> "In an ideal world we'd want social flourishing at all stages, but the resources required would be enormous and we have to be pragmatic. People have different wants and needs…especially in a care home environment, it might be impossible to satisfy everyone's wants and needs in a single environment." (Telephone, NGO)

On the other hand, other participants took a more aspirational standpoint:

> "I think it's about being more creative about what the social flourishing goals are…so the guy who you thought couldn't have a conversation, if we can change how we communicate with them… it's just finding the thing with him, whether it's singing or something else…" (Group 1, Social Enterprise)

The debate between pragmatism and aspiration is important in both theory and practice. In favour of keeping aspirations high, it has been argued that maintaining a universal definition of well-being respects the equal human dignity of people with impairments, and avoids the creation of 'tiers' of humanity: defining a group of people in terms of their impairment, rather than their humanity, is stigmatising and treats them as second class citizens. Down-grading social goals in relation to people with impairments is often "an easy way of getting off the hook" in terms of aiming for goals that may be expensive or difficult to achieve (Nussbaum 2007:190). The participant (quoted above) who spoke about "being more creative" about the goals provides a clear, practice-based view that, while some elements of well-being are universal, there is room for manoeuvre ('creativity') in specifying in more detail how these universal goals are defined and achieved in practice.

Living well with dementia in the community

For people with dementia living in the community, the capability of family carers to give care is fundamentally important. One barrier identified in relation to this was that many family carers do not identify themselves as 'carers', so are often unaware of the support available. This highlights the importance of "proactive awareness" among primary health practitioners and other front-line public service providers of the need to support carers.

As well as support for family carers, paid carers' capability to care is also important:

"But if you've only been given 10 minutes to get somebody dressed, it's really hard. There doesn't seem to be much comprehension amongst people who assess these things that someone with dementia could be dressed when you arrive, or it could take two hours, you know, you're given 10 minutes." (Group 1, Local Authority)

This quote points to the tensions that can arise between the resource constraints of care providers and carers' ability to support people to live well. It also highlights a perceived lack of flexibility in the way care work is sometimes planned and organised. The capability of paid carers depends on the freedom they have to move away from 'task-oriented' care to 'person-centred' care (McCormack and McCance 2011). This points to a further, related tension for care providers between the accountability that can be achieved through the measurement of quantifiable tasks and outcomes, and the need for carers to engage with people as human beings, in ways that may be less easy to measure and account for.

Living well with dementia in care homes

It is estimated that four out of five people living in care homes in the UK have some form of dementia or severe memory problem (Alzheimer's Society 2015). For those living in care homes, the social and material environment within the home and the capability of carers to give adequate care were important themes. As well as designing rooms to facilitate interaction and providing safe and accessible outdoor spaces (see Section 2.1), one strategy that was considered effective was training all staff members – including, for example, kitchen and laundry staff – to engage and interact with residents (for example through "empowered conversation" training); again, the weaker ties of affiliation are a key enabler.

This links to the importance of treating each person as an individual and being sensitive to and supportive of their individuality and their social- and self-identity. The idea of 'person-centredness' is prominent in discourses around care; however, the difficulties in providing tailored, individualised care on a large scale were acknowledged by participants. Resource constraints are an important barrier in this context; however, many strategies identified were low cost or cost free:

"…all the staff [in the care home] wear something like pyjamas at night, and they find that if you walk into the bedroom of someone who's up at night, they're cued in immediately that it's night time." (Group 2, Charity)

"Somebody with dementia might stop recognising day and night, and might therefore start to, if they keep being told to go to bed, actually they're going to be distressed, they don't think it's time to go to bed, they think it's time to go to work or to be going out to pick the children up.

So if a care home was doing good quality dementia care they might be in their pyjamas…and actually that doesn't cost any more money whatsoever…" (Group 2, Local Authority)

This suggests that the need for creativity around the *ends* (goals and outcomes - see section 2.1) can be extended to creativity around the *means*, and this can have advantages in terms of both better care and use of resources:

"There isn't any more money in the system to do any of that work, so you can't expect that you can start to commission vastly expensive specialist services. But actually there needs to be an expectation that the traditional models of care are not fit for purpose for people with dementia…from a public service point of view, we're in a state of huge financial crisis really, but you know, a lot of this isn't about it costing more, it's about just a shift in a way of working and a perspective." (Group 2, Local Authority)

The role of adult health and social care services in enabling people to live well with dementia is clear, both for those living in the community and those in care homes: the institutional environment of dementia care policy provides the framework within which people live with dementia. The engagement of public service commissioners is therefore a crucial prerequisite of effective and ethical service provision:

"It's about the education of the people in those positions who have responsibilities to make decisions about how services are organised, planned and arranged, that in some cases is lacking as well, about what actually it means to live well, and then being able to translate that into service specification to be put out to tender." (Group 2, Local Authority)

A major barrier in this context was identified as the difficulties in measuring and evaluating services and programmes in the context of dementia.

"The befriending we do, it's really hard from the commissioner's point of view to say 'well what has that achieved', but actually you can tell that it is having an impact, but whether you can say it's prevented them from going to hospital, it's really hard because it's quite a soft thing." (Group 1, Local Authority)

There was some reflection among the groups about how services are evaluated, and the measurement of outcomes that may not be the most important ones:

"I think we measure the wrong things…in care in general and dementia care in particular, it's very task focused, and we want to know, you know, how many people have been into the day centre, you know, have you dealt with personal care…it means actually we can be contract compliant without delivering very good care."

(Group 2, Local Authority)

The difficulty of deciding what to measure and evaluate in the context of public service provision highlights the importance of a clear definition of living well with dementia, as the basis for designing and evaluating effective and ethical care policy and practice that keeps the dignity of the person at the centre of both means and ends.

Part 3. Discussion and Conclusion

The aim of this study was to examine the idea of 'living well with dementia': to identify the most important aspects of what it means to live well with dementia, and how this can be achieved. It was proposed that there is a 'universal core' of well-being in dementia. Through analysis of the literature and empirical evidence, the study sought to identify the content of this universal core.

This stage of the research focused on the views of policy-makers, commissioners and providers of dementia-care services. These views provide an invaluable perspective that is embedded not only in direct experience of working with people with dementia, but also in the political economy of the health and social care sector. This is, of course, only a partial view, to be expanded by future research with people living with dementia.

Part 1 of the report highlighted the value of the social model of disability for dementia policy and practice. The social model defines living well as a result of the interaction of features of a person, and the material, social and political environment in which they live. Similarly, the research adopted a social definition of personhood and well-being, understanding these as relational (not individual) concepts. The research is also based on the fundamental idea that ensuring that people with dementia can live well is not merely a matter of charity or compassion, but an issue of social justice.

Living Well with Dementia: The Evidence

The evidence suggests that living well with dementia is certainly possible. Contrary to much popular opinion, people living with dementia do not necessarily lose the capability to live well. They retain many of the central concerns and needs common to all human beings; there are some universal aspects of living well that are as important for people with dementia as they are for anyone else. However, creativity is needed to re-specify the details of living well *with dementia*.

Affiliation as a catalyst

Analysis of the literature revealed broad consensus around the importance of social relationships, and the empirical research supported this finding. Close personal relationships are a crucial part of living well with dementia *together*. The capability of carers to care emerged as a crucial matter in this regard; support for the well-being of family members and carers, as well as of people with dementia, is a necessary condition for enabling people to live well together.

At well as close personal relationships, weak ties of affiliation – for example, patient and understanding service workers and passers-by who are willing to help – can give a person with dementia the freedom to participate in the life of her community. A dementia-friendly social environment can help to reduce

social exclusion. At its best, social inclusion respects the personhood and equal dignity of the person with dementia, which diminishes the stigma associated with a condition that is surrounded by fear and misunderstanding in the public realm.

Affiliation may be thought of as a 'fertile functioning' (Wolff and de-Shalit 2013): as well as being important in its own right, it is also a catalyst for other valuable outcomes, from physical health to emotional well-being. For policy, this suggests that when resources are limited and practical decisions must be made between multiple valuable goals, a sensible strategy would be to prioritise support for social relationships.

Emotional well-being

The evidence suggested that the subjective experience of people with dementia has special importance. Cognitive impairment in areas such as memory and communication can mean that many people with dementia may be living predominantly "in the moment": as other areas of cognitive capacity become diminished, emotional well-being takes on heightened priority. However, despite its importance, living well is not reducible to emotional well-being; emotional well-being is better seen as a necessary but not sufficient condition for living well.

Emotional well-being was considered by participants to be a fundamentally relational concept, dependent on communication and connection with others. Self-respect and self-concept were seen as being generated by interaction with others, including close family and friends, as well as other people such as staff in a care home, service workers in the wider community, and the general public. Creativity and flexibility are needed in how 'relationships' and 'communication' are defined and understood, since these often take different forms in the context of dementia. For example, relationships may come to be constituted more by episodic moments of shared experience, rather than continuous, narrative-style communication and interaction.

Identity and agency

The empirical evidence was also insightful with respect to the complex issues surrounding identity and agency in dementia. Participants agreed that agency and identity should be understood as relational concepts, dependent on affiliation. Security of self-identity is also a fundamental part of emotional well-being. Participants suggested that personal identity in some form remains, even in advanced stages of dementia, and this can be evident in people's continuing capability for affiliation.

Finally, from an institutional and policy perspective, participants emphasised the role of service providers and service commissioners, whose job it is to find the right balance between a plurality of

valuable outcomes for different people in different contexts, and to set up and monitor the processes that will deliver these (and all this in a context of resource constraints). Given the dependence of people with dementia on others, and the importance of the social and institutional environment in supporting people to live well, proactive, positive support, rather than the mere removal of obvious barriers, should be a guiding principle.

Risk aversion among some providers and 'measuring the wrong things' were identified as barriers to living well. Whether a process or policy is empowering or demeaning can be difficult to capture in a straightforward, standardised way. Participants suggested that freedom to try new approaches, and the prioritisation of 'person-centredness' in the design and evaluation of services, are important general principles. Another balancing requirement – that between accountability and good care – is evident here.

Conclusion

This study has examined the objective set out in the UK National Dementia Strategy that "All people living with dementia and their carers should live well with dementia." The findings show that it is undoubtedly possible to live well with dementia. They also show that living well is fundamentally a social idea, and the ability to live well with dementia *together* depends on relationships of care and solidarity, and on the social, political and material environment. This confers a duty on society to strive to make the possibility of living well with dementia a reality.

We have advocated a 'social pluralist' definition of well-being in dementia: well-being is multi-dimensional, and generated through, and embedded in, social relationships. A set of interlocking ideas around social connection, communication, identity and emotional well-being emerged as the universal core of living well with dementia. Social relationships are centrally important in their own right, and are also the basis of many other aspects of a good life. The social inclusion of those living with dementia should be high on the policy agenda.

Finally, both the means and the ends are important in enabling people to live well with dementia. Enabling people to achieve valuable outcomes through policies and processes based on respect for human dignity is enabling and empowering, instead of disabling and demeaning.

In conclusion, this study has found that the idea of 'living well with dementia' applies not just to those directly affected, but also to how we, as a society, live well with dementia together.

Appendix 1: Fieldwork information

Recruitment

The following email invitation was sent to a subset of the MICRA network, selected on the basis of their job title and organisation, and their role as decision-makers or practitioners in the field of dementia:

> Subject line: Dementia, Well-being and Vulnerability
>
> Dear X
>
> The University of Manchester (MICRA) and Age UK are sponsoring a new research project on 'Living Well with Dementia'. The objective of the research is to increase our understanding of the individual, social and environmental factors that enable people to live well with dementia. The project aims to contribute to evidence about what can be done, in terms of dementia care policy and practice, to enhance the well-being and reduce the vulnerability of people with dementia.
>
> We would like to invite you to take part in a small group discussion on this topic. The discussions will include up to five people, all of whom work in some capacity in the field of dementia care. Participation would involve a one-off discussion, lasting around 90 minutes, at the University of Manchester Oxford Road campus (travel expenses will be reimbursed).

An advertisement was also placed on the MICRA website:

> **Participants required for group discussions on 'living well with dementia'.**
> Do you work with or for people with dementia? Researchers at the University of Manchester, would like to invite you to participate in a small group discussion about what it means to 'live well with dementia'. Participation would involve a one-off discussion of up to five people who work in dementia care. Discussions will last around 90 minutes, and take place at the University of Manchester Oxford Road campus.
>
> The aim of the research is to develop a better understanding of the individual, social and environmental factors that enable people to live well with dementia. The objective is to set out a full account of the determinants of 'well-being' and 'vulnerability' in the context of dementia care, with the aim of illuminating what can be done, in terms of policy and practice, to ensure that people with dementia and their carers are able to live well.

Topic guide (Discussion groups and telephone interviews)

Dementia, well-being and vulnerability

What is important for a good quality of life for people living with dementia?

- What kinds of things is it important that people are able to achieve in their lives?
  - Specific – apply particularly to people living with dementia (and different types and stages of dementia)
    - E.g. understanding what's going on and communicating
  - General - apply to all people, whether they have dementia or not
    - E.g. good social relationships
  - How are these things related, how do they interact? How are the more general things influenced by living with the disease?

- What are the factors that influence the ability of people living with dementia to have these valuable things in their lives? What might enhance people's ability to achieve them, or lead to losses in people's ability to achieve them?
  - Individual
  - Social
  - Environmental

- Personal autonomy, making your own decisions: typically seen as important for well-being. (How) does this concept apply in the context of dementia care, for people whose mental capacity is affected by the disease?

- Areas for improvement: what could be done in different settings and scenarios, with reference to different groups (e.g. people with dementia, family carers, paid carers, the wider community), to reduce vulnerability and enable people to 'live well with dementia'.

Handout

What do people living with dementia consider important in life?

1. Relationships or someone to talk to
2. Environment
3. Physical health
4. Sense of humour
5. Independence
6. Ability to communicate
7. Sense of personal identity
8. Ability or opportunity to engage in activities
9. Ability to practise faith or religion
10. Experience of stigma

Source: Alzheimer's Society (2010), 'My Name is Not Dementia: People with dementia discuss quality of life indicators.'

Appendix 2: Central Human functional Capabilities (Nussbaum 2000)[4]

1. Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.

2. Bodily health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

3. Bodily integrity. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

4. Senses, imagination, and thought. Being able to use the senses, to imagine, think, and reason—and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.

5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. Practical reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)

7. Affiliation. *(A)* Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) *(B)* Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, ethnicity, caste, or national origin.

8. Other species. Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. Play. Being able to laugh, to play, to enjoy recreational activities.

10. Control over one's environment. *(A) Political.* Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association. *(B) Material.* Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

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[4] The headline domains on the list ('Life', 'Bodily Health' and so on) are specified as universal political entitlements. The detail in the original list (above) relates to women in developing countries. Nussbaum (2000) endorses an approach that maintains the headline domains, but tailors the detail to different target populations (in our case, people with dementia).

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