

# *Alzheimer Europe Report*



**The ethical issues linked to the perceptions and portrayal of dementia and people with dementia**

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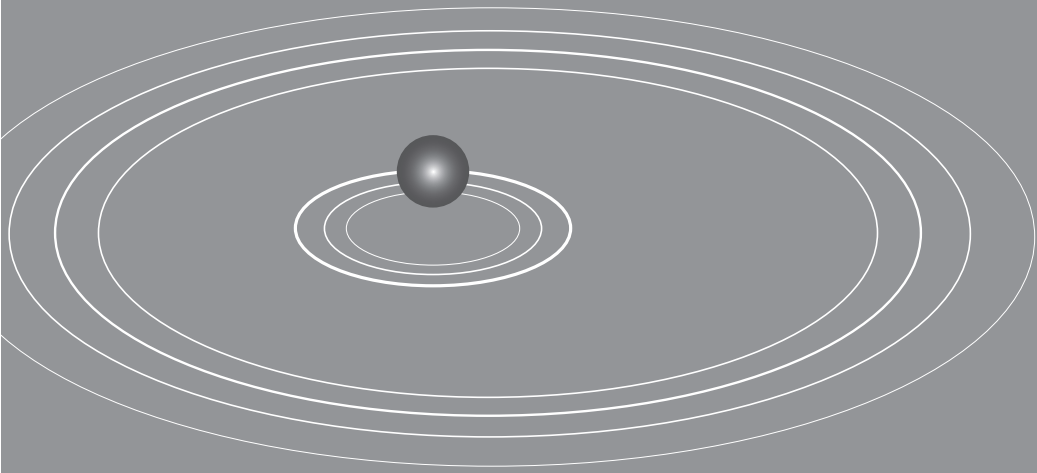
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*Preface/Foreword*

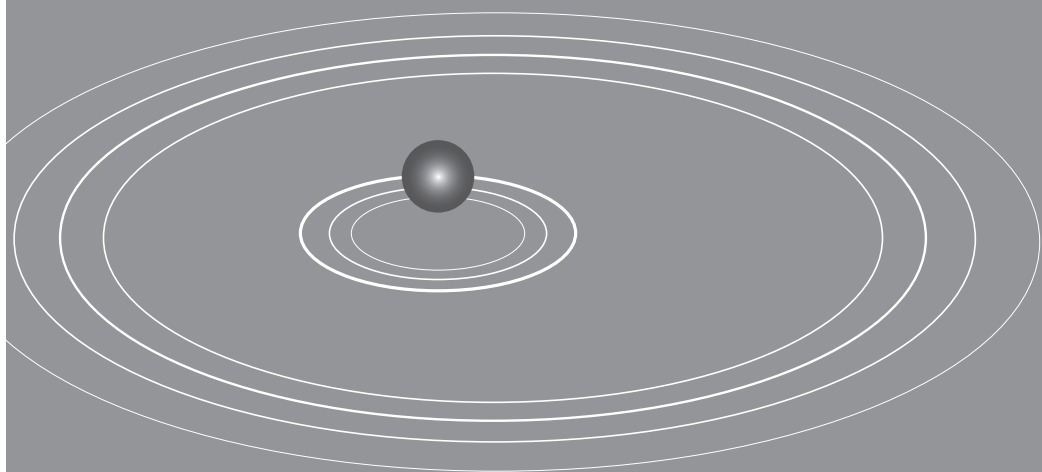
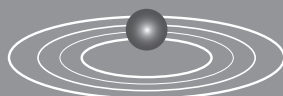


It is with great pleasure that I present this report which explores the way that people with dementia are both perceived and portrayed within society and which reflects on the ethical implications of this. The way we look at dementia differs from one person to the next and according to the situation or context. This report provides a non-judgemental overview and reflection on the possible consequences for people with dementia and their carers of the different ways that members of society perceive dementia and communicate those perceptions to others (in words, images and through policies and actions).

The report is the result of the work by a multidisciplinary group of experts in old age psychiatry, psychology, dementia, philosophy, cultural sociology, nursing and media studies, as well as a person with dementia and carers. The members of the working group generously donated their time and expertise throughout 2013 and in so doing, made it possible to publish this report. I would therefore like to express my gratitude to Dianne Gove (Chair), Debby Gerritsen, Bénédicte Gombault, Fabrice Gzil, Jana Kasparkova, Jan Oyebode, Sirpa Pietikäinen, Christine Swane, Baldwin Van Gorp, Aino Valtanen, Daphne Wallace and Richard Wallace.

I hope that this report will contribute towards increasing awareness of the many different ways of looking at dementia, and to the realisation that dementia is not only a medical condition but also a complex social phenomenon. I trust that the report will encourage reflection on the importance of the meanings that we construct around dementia and the development of a more inclusive, respectful and nuanced understanding of dementia. Finally, I hope that you enjoy reading about the many different ways that dementia is perceived and portrayed and that the sections on the related ethical issues lead to further personal reflection and have a positive impact on your attitudes, feelings and possible future experience of dementia.

Heike von Lützu-Hohlbein  
Chair  
Alzheimer Europe



*Summary/synthesis*

In 2009, Alzheimer Europe established the European Dementia Ethics Network with the aim of encouraging ethical reflection on a range of topics of relevance to the lives of people with dementia and their carers. This report reflects the work carried out by a multi-disciplinary working group within the framework of that network to describe the different ways that people with dementia are perceived and portrayed within society and to consider the ethical implications of this. On the basis of an extensive literature search, we explored the perceptions and portrayals of dementia of different groups in society (e.g. the general public, people with dementia, carers and healthcare professionals, to name but a few), the use of language and the influence of the media and film-makers. Our ethical reflection focuses on ways in which various ways of perceiving and portraying dementia are likely to be beneficial or potentially harmful to people with dementia (e.g. in terms of their dignity, wellbeing, autonomy, rights, personhood, relationships and role in society).

Part 1 sets the scene by explaining how the work was organised and why this topic was chosen. Clearly, there are as many different perceptions of dementia and ways of portraying it as there are people. We have tried to group together those which were similar in some way into a meaningful structure.

Part 2 starts with an overview of explanatory models, which reflect how people make sense of dementia. On the one hand, a historical development can be detected in the focus on certain models at different points in time but on the other hand, some cultural differences were detected and also, it is clear that the various models are not exclusive. For example, some people perceive dementia as part of natural ageing, a biomedical condition or a mental disorder, and at the same time as a disability or due to spiritual forces.

The words and metaphors that people use in connection with dementia are rich in symbolism and significance, sometimes used strategically to achieve certain goals, sometimes used without much reflection. The impact of the language surrounding dementia is considerable and reflection on the possible ethical implications suggests that, albeit with a few exceptions, there are very few expressions which can be considered as wholly “good” or “bad”. For one person a word or metaphor might represent hope or help them to cope, whereas for another it sums up dread and loss of the self. Some words and metaphors are used liberally and paint a very biased picture of dementia, whilst others are avoided and considered demeaning, depersonalising and insulting. Even standard medical terms are sometimes used with great caution due to an awareness of the possible impact on people’s lives and wellbeing. Words clearly matter. They describe, communicate and reinforce our current perceptions of dementia. With awareness, we can try to use them positively to challenge portrayals of dementia and promote a more positive image of dementia and people with dementia.

An exploration of the way in which the existence and experience of dementia are perceived and portrayed reveals a range of philosophical beliefs about what it means to be a person and how dementia affects this experience and state of being. Turning to the perceived characteristics of dementia, we find a few key stereotypes and rather limited perception of how people are affected by dementia, what they look like and how they act. Here the challenge perhaps lies in acknowledging the diversity of people with dementia, interacting with them and reflecting on the numerous factors which influence how they are perceived, portrayed and subsequently treated.

This report reflects a social constructivist philosophy of the way that we make sense of the social world in which we live, which emphasises the importance of interacting with others in a process of meaning making. In today's society, we are also influenced by the media and films. We therefore reflect on the concept of frames and counter-frames, as a means to present a more nuanced and hence realistic perception of dementia and on the way that the portrayal of dementia in films affects people emotionally and influences their understanding and expectations in relation to dementia.

Having described numerous ways of perceiving and portraying dementia, we consider in Part 3 how this relates to the experience of people with dementia and to what they are telling us. We also highlight some of their reactions towards the way that others perceive and portray them.

In Part 4, we end the report with a few concluding remarks in the form of general guidelines to encourage a balanced perception of dementia and to consider when addressing, referring to or portraying people with dementia. These remarks draw on in-depth reflection on the possible impact of various perceptions and portrayals of dementia. It is hoped that this report will contribute towards the recognition of people with dementia as unique, valued individuals and the promotion of their dignity, wellbeing and rights through greater attention and sensitivity to the way they are perceived and portrayed.

## 1. *Introduction*

### About perceptions and the portrayal of dementia

People make sense of dementia through the meanings and explanations they construct as a result of their personal observations and experience, and through their direct and indirect interaction with other people. Their perceptions, not entirely conscious or deliberate, reflect complex processes of attending to certain factors and disregarding others. Perceptions develop through interaction between what people see and hear and their past experience, knowledge, beliefs and expectations. Perceptions of dementia are also influenced by official discourses from governments, scientists and other groups with expert knowledge or specific motives. Such perceptions and discourses are promulgated through official channels, culture, education, the healthcare system, entertainment and the media. Certain characteristics and ways of making sense of dementia become emphasised whilst others are given little or no attention.

Perceptions are often expressed through words and may be associated with images, including metaphors. Words and images can be powerful and affect the way that we think about the concepts to which they apply, such as dementia and people with dementia. George (2010) describes this in terms of a moral challenge linked to semantic choice, whereby subtle alterations in the way that we talk about certain conditions may contribute to more humane approaches to them. This may, in turn, affect the way that people with dementia are treated within society.

The way that people perceive dementia contributes towards the way that they portray it to others within the social and professional domains in which they operate and, vice versa, the way that dementia is portrayed affects how it is perceived. A balanced portrayal of dementia is needed. It is important to understand the way that people from all walks of life (such as the general public, people with dementia, carers, film producers, healthcare professionals, scientists and politicians) perceive and portray dementia as they are all involved in the social construction of meanings associated with dementia (i.e. definitions, understanding) and, hence associated feelings about dementia.

In this report, we have tried to give equal importance to different perceptions and portrayals of dementia and to maintain a neutral stance when describing them. However, we realise that we are part of the society in which the meanings that have come to be associated with dementia are constructed. Such meanings are not static. They are constantly being challenged and renegotiated within a particular social, cultural and historical context and we can, at best, simply claim to have tried to be objective. Brief details of the background of the authors behind this text can be found in Appendix 1.

### People with dementia (“us” not “them”)

This report is about how dementia and people with dementia are perceived and portrayed. This unavoidably singles out a group of people who share a common characteristic, namely dementia. People with dementia are present in all sections of society and are a heterogeneous group. Dementia is just one aspect of their identity to which they may accord varying degrees of importance. People with dementia are part of the society which perceives and portrays dementia, and in which the meaning and significance of dementia are constructed. In this report, their perspective on this topic is mentioned, where known,

in relation to the various sub-topics addressed, but also separately at the end of the report in relation to the general issue of the way that dementia is perceived and portrayed within society. We will occasionally refer to people with dementia as “they” in order to avoid repetition and clumsiness of expression. However, we would like to emphasise that “they” (i.e. people with dementia) not only have dementia but are at the same time our friends, colleagues, neighbours, partners, and relatives and, in some cases, our children or indeed ourselves. The designation of people with dementia as a separate group should not be considered as reflecting the core feature of their identity but just one common feature amongst a multitude of others which differ.

## Explanation of key concepts

### ***Dementia***

A report about the way that dementia is perceived and portrayed requires, for the sake of clarity, some kind of explanation as to what dementia is. The following definitions are taken from the website of the Alzheimer’s Society of England, Wales and Northern Ireland:

*“The term dementia describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. There are many types of dementia. The most common are Alzheimer’s disease and vascular dementia. Dementia is progressive, which means the symptoms will gradually get worse.*

*Alzheimer’s disease, first described by the German neurologist Alois Alzheimer, is a physical disease affecting the brain. During the course of the disease, protein ‘plaques’ and ‘tangles’ develop in the structure of the brain, leading to the death of brain cells. People with Alzheimer’s also have a shortage of some important chemicals in their brain. These chemicals are involved with the transmission of messages within the brain.”*

There are also a range of national, European and internationally recognised definitions and diagnostic criteria which serve to determine whether a person has dementia and to identify the type of dementia that s/he has. Dementia and the associated diseases are often defined in terms of symptoms and typical prognosis. However, as pointed out by the Alzheimer’s Society (2012), “While there are some common symptoms of Alzheimer’s disease (AD), it is important to remember that everyone is unique. No two people are likely to experience AD in the same way”.

As will become clear as you read through this report, the above brief definitions of dementia and AD reflect an explanatory model which is fairly medically orientated. This should not be interpreted as reflecting the full understanding of dementia and AD of the Society quoted as the quotes are selective. Moreover, people do not all perceive dementia in the same way and even those who share the same understanding or accept the same definition may perceive the experience of dementia, its impact on people’s lives and on society, as well as the way that people with dementia are considered by society and treated, in different ways. Apart from the fact that people do not all consider dementia or the various forms of dementia a medical condition (please see the section on explanatory models of dementia), medical definitions of dementia are insufficient to understand what dementia actually means to people. The words and metaphors that people use when talking about dementia, the associations they make between dementia and other concepts and the way

that dementia is portrayed all provide insight into the emotional, psychological and social significance that it has for different people.

### ***Stigma***

Dementia (and its various forms) has been described as a stigma by lay people and health-care professionals (e.g. Alzheimer's Society, 2008; Batsch, Mittelman & Alzheimer's Disease International, 2012; Gove, 2012; Nolan et al., 2006; Swane, 1996, Vernooij-Dassen et al., 2005; Werner and her colleagues), numerous Alzheimer associations, national governments (as expressed in national dementia plans), the European Commission (2009) and the World Health Organization (2012). References to dementia as a stigma can also be found in personal accounts by people with dementia and informal carers. Often, a clear definition of what is meant by stigma is lacking. For some people, it might be used to refer to dementia being a taboo or something shameful, for others the devaluation of people with dementia and for yet others the attribution of a negative label or in relation to perceived discrimination against people with dementia. As frequent reference is made to stigma in connection with the ethical implications of various ways of perceiving and portraying dementia, some clarification is first needed as to what we mean by stigma.

In Goffman's seminal work on stigma, the term is used to refer to the attribute which is deeply discrediting in that it reduces someone in other people's minds from a "whole and usual person to a tainted, discounted one" (Goffman, 1963, p.12). Through the process of attribution of meaning, particular attributes come to be linked to dispositions that discredit the bearer and "spoil" his/her identity (Jones et al., 1984, p.8). It is the social meaning and significance that people attribute to various attributes which make them discrediting and the psychological and social consequences of the attribute, rather than the attribute itself, which often have the strongest negative impact on those who have it. People who develop dementia are likely to be aware of the way that it is perceived in society, irrespective of whether they share, internalise or challenge those perceptions.

The term stigma is also used to describe a complex social phenomenon or process (sometimes called "stigmatization"). For Link and Phelan (2001; 2006), stigma is conceptualized as the convergence of a set of components: labelling, negative stereotyping, separating "us" from "them", emotional reactions, power, and status loss and discrimination. Attribution models of reactions to stigma focus on whether people with a particular stigma are considered as being either dangerous or responsible for having it (Corrigan et al., 2003; Weiner et al., 1988). In addition, there are factors which are believed to increase the likelihood of a particular attribute becoming a stigma. These include concealability (the extent to which it is visible or can be hidden), course of the mark (whether it becomes progressively worse), disruptiveness (whether it hinders or strains interaction with other people), aesthetic qualities, origin (whether the person is responsible for having it) and peril (Jones et al., 1984) or threat (i.e. what is worrying or threatening about the stigma) (Stangor and Crandall, 2003). The following definition focuses on health-related stigma.

*"Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. The judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to the persons or group, the discrimi-*

*natory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma which results from adverse social judgments about enduring features of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences) may also affect health; these are also matters of interest that concern questions of health-related stigma.” (Weiss and Ramakrishna, 2004, p. 13)*

So much has been said and written about the stigma of dementia that it might sometimes be considered as a fact that dementia is a stigma. This is only the case to the extent that it continues to be socially constructed as such and that this is reflected in the way that people with dementia are perceived, portrayed and treated by others, as well as in the way that they perceive themselves as having a stigma. Link and Phelan (2001) use the term label to refer to the observed socially salient attribute (in this case dementia) rather than the term stigma. A label, they claim, is something that is affixed and makes no claims about the validity of the designation. This challenges the taken-for-granted nature of socially salient differences. Nevertheless, many of the issues covered in this report reflect the various components, contributing factors and consequences associated with it. Consequently, stigma is a recurring topic.

### **Ethics**

Ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong. It is therefore closely linked to morality in that it is about what morally ought to be the case rather than how things necessarily are. It is about how we ought to act towards one another and covers numerous decisions we make in everyday life, including those with implications for life or death (Mattiasson and Hemberg, 1998).

There are different approaches to ethics. Communitarian ethics maintains that moral thinking has its origins in the historical traditions of particular communities. Consequently, it is a cultural rather than abstract concept in that communities share values, customs, institutions and interests. However, an over-emphasis on communitarian ethics might result in a “tyranny of the majority” in which the majority defines what is beneficial, morally right or “a good life”, which may result in an unfair outcome for some groups of people (Petrini, 2011). Some ethical principles are widely accepted across cultures, such as the ethical principle ‘do no harm’, though the subject, object and nature of harm varies across temporal and cultural contexts.

Some approaches to ethics focus on the outcome, judging whether the consequences of an act are good or bad (Noble-Adams, 1999) or what the best outcome would be for the greatest number of people (Peach, 1995 in Aita and Richer, 2005). Another approach involves considering whether the nature of an act itself is right or wrong irrespective of the consequences because something is believed to be good if it is consistent with moral rules and principles. This is often described as a deontological theory and a classic example is Kant’s theory.

There are several ethical principles which are frequently mentioned in the context of health-care and ethics. Perhaps the most well-known are autonomy, beneficence, non-maleficence and justice (Childress and Beauchamp, 2001). The capacity for autonomy has been conceptualised in different ways. For clinicians, the capacity for autonomy tends to be conceptualised in terms of the capacity to make meaningful decisions (according to Appelbaum in



relation to specific tasks), whereas for moral philosophers, the emphasis is on the capacity to have what Dworkin describes as “critical interests” and Jaworska as “values” (Gzil, 2011). “Care ethics” places particular emphasis on the care relationship/process (characterised by reciprocity), on being receptive to what happens to the person, and on respect and trust (Mahieu and Gastmans, 2012). Related concepts include dignity, singularity (focusing on the unique nature of each person), historicity (reflecting the historical dimension of human existence) and relationality (considering what is meaningful to each person in terms of their relationship to others). Such concepts are relevant to the way that people with dementia are considered and treated within society irrespective of whether they are receiving care. Finally, Petrini (2011) argues in favour of an ethical approach based on “personalism” which strives to achieve common good by promoting and enhancing the good of the individual guided by values such as respect for life, sociality and solidarity, and responsibility.

### **The importance of looking at the way dementia is perceived and portrayed**

The way that people perceive and portray dementia can have implications for the way that people with dementia are valued and treated, and how dementia is addressed within society (e.g. with regard to the standard of care they receive, the importance given to medical treatment, their involvement in research and the kind of research carried out, social inclusion and the extent to which their human rights are respected). This may have a positive or negative impact on the lives of people with dementia, now and in the future, individually and as a group. Perceptions are communicated to people with dementia through words, gestures, intonation and even avoidance. In addition, people develop dementia. They were not born with it and it is likely that throughout their lives, they also had certain perceptions of dementia. Consequently, when a person suspects or finds out that they have dementia, those perceptions may influence their expectations in relation to their future lives and to how they will be treated by other people, as well as their self-concept and self-esteem.

Firstly, the expectations, fears and beliefs about dementia may affect people’s readiness to seek a diagnosis. Several studies confirm high levels of fear amongst lay people (Cutler and Hodgson, 2001; Pin-le-Corre and Cantegreil, 2009; Tsolaki et al., 2009; Werner, 2002; Werner and Davidson, 2004; Wortmann et al., 2010). In a survey carried out by the Harvard School of Public Health and Alzheimer Europe involving 2,678 randomly selected adults from France, Germany, Poland, Spain and the US, participants were asked to choose which disease they were most afraid of getting from a list of seven diseases including cancer, heart disease and stroke (Blendon et al., 2012). Around a quarter of adults in four of the five countries stated that they most feared having AD. Although some studies have indicated complacency amongst the general public about developing dementia (Lee et al., 2010; Low and Anstey, 2009; Sahin et al., 2006; Yeo et al., 2007), it was cited as the second most feared condition after cancer in all countries except Poland.

Diagnosis can be beneficial provided that it is timely and not just early or too early, helping people to understand changes they are experiencing, giving them the opportunity to make plans for their future whilst they are able to do so and enabling them to give informed consent to current treatment and support. In many cases, diagnosis opens the door to treatment, care and support, which can sometimes be beneficial to informal carers who provide much of the care and support needed, and often have other personal and professional commitments alongside. Certain perceptions of dementia may hinder help-

seeking such as the perception of AD and other forms of dementia as being part of the natural ageing process, due to spiritual forces, something to be ashamed of or a stigma.

Stigma has been associated with delays in timely diagnosis (Cahill et al., 2008; Gove, 2012; Husband, 2000; Iliffe et al., 2003; Kaduszkiewicz et al., 2008; Pentzek et al., 2005; Van Hout et al., 2000; Vernooij-Dassen et al., 2005) and is also believed to interfere with the disclosure of the diagnosis, which is part of the diagnostic process (Bamford et al., 2004; Boise et al., 1999; Brodaty et al., 1994; Cahill et al., 2008; Iliffe et al., 2005). This may lead to inequity in the provision of care as people with dementia, compared to people with other conditions, are not accessing the care they need. Also, they may be left in doubt or ignorance that they have dementia, whilst other people have such information about them. They are denied the opportunity to make truly informed decisions about their care, treatment and future lives, and may even be placed in a vulnerable position.

The way that people perceive and portray dementia reflects the meanings they attribute to it. It is therefore essential to look at those perceptions and portrayals. Through awareness and reflection on how people make sense of dementia, how they feel about the prospect of one day having dementia and about the different ways they talk about and represent dementia, it may be possible to gain insight into those meanings. Such insight forms the basis for possible change, where change might be beneficial for people with dementia and their carers, and for the promotion of positive attitudes and behaviour which are conducive to respecting their personhood, individuality, wellbeing and human rights.

### **Ethical reflection on the way that dementia is perceived and portrayed**

To date, Alzheimer Europe's work on ethical issues has focused on issues which involve some form of action such as the use of assistive technology, the provision of end-of-life care, carrying out research and the restriction of freedom of people with dementia. Although the portrayal of dementia often involves communicative action, such as writing, talking and acting, perceiving and portraying dementia involve thought processes and beliefs, which may sometimes be intentional and sometimes not. This makes the overall theme of this year's report slightly more abstract.

Most people consider what they perceive as "reality" or "fact" and many perceptions are taken for granted as shared realities, in that people have co-constructed them within society through interaction with other people. This reflects the social constructivist paradigm, which rests on the assumption that there is not one single reality or truth which, if we tried hard enough, we could discover. Rather reality is understood as being multiple and constantly in the process of construction. Different people have different realities. Many of these realities are shared as they are constructed and negotiated (and even challenged) through interaction with other people, either personally or through shared cultural, educational and social channels. However, different people have different subjective realities.

Consequently, it is difficult to say that one person's perception is "wrong" or "unethical" because it is simply their reality born out of their social, cultural, cognitive and emotional experiences. The same could be said for the portrayal of dementia provided that people portray dementia as they perceive it and not based on ulterior motives.

Even though our perceptions result from complex and often unconscious processes, nevertheless, the way we perceive and portray dementia has implications for the way that


we act towards people with dementia and how we address the issue of dementia within society (e.g. in terms of care, treatment, social inclusion and human rights). Such acts may have a positive or negative impact on the lives of people with dementia, now and in the future, individually and as a group. We can therefore reflect on the possible consequences of various perceptions and portrayals of dementia in relation to a range of ethical principles and concepts.

Perceptions cannot simply be changed. Without a full understanding of the individual, social and cultural context of each perception or portrayal described, we cannot judge which perceptions and portrayals of dementia will contribute towards unethical treatment or be potentially harmful to people with dementia. Furthermore, we acknowledge that each perception and portrayal could be interpreted differently and reflect different meanings for different people. We therefore seek to raise awareness and foster reflection about the possible ethical implications for people with dementia (and future generations of people with dementia) of being perceived or portrayed in certain ways.

Our aim is not to enter into philosophical debates about dementia-related concepts or to take a position on their accuracy, logic or desirability, but simply to present the perceptions and portrayals of non-philosophers and consider the possible ethical implications of these for people with dementia.

### The structure and scope of the report

In Part 2 of this report, we address the way that dementia is perceived and portrayed, covering a range of explanatory models (reflecting understandings of the origins or cause of dementia), the characteristics of dementia and people with dementia and the perceived impact of dementia. We also look at how dementia has been portrayed in the media and films. In Part 3, we look at the perceptions of those who are perceived and portrayed, namely the perceptions of people with dementia themselves, as well as their reactions to current perceptions and portrayals of dementia. Finally, in part 4, we present a set of conclusions which might offer guiding principles to bear in mind rather than guidelines on how to act.

The sections in the report entitled “ethical implications” (at the end of each sub-section, or in some cases at the end of a group of sub-sections) are derived from the ethical reflection of the working group and provide an overview of ethical arguments and conclusions in relation to the topics discussed. There are very few references in these sections, as the points made are the reflections of the working group and not based on knowledge derived from empirical studies, established causal relationships or personal testimonies. Where we have grouped together two or three linked topics within a main theme, we address the related ethical issues at the end of that sub-section. This is then separated from the subsequent topics within that theme by a divider – .

We address a wide range of issues in our report but several areas are not covered. For example, we did not address the way that dementia is portrayed in educational materials and awareness raising campaigns, or the way that it is perceived and portrayed by Alzheimer associations, government agencies and policy makers. This was primarily due to time constraints and the need to limit the overall length of the report. Also, when reflecting on various ethical issues, we address some topics which could also be considered as perceptions of dementia (particularly in relation to stigma and some of

its components and contributing factors). To avoid repetition, we have addressed these topics mainly in the sections on related ethical issues and not as separate sections in Part 2 of this report.

## The working group and methodology

The report is the result of deliberations by a working group which was specifically set up with the aim of identifying different ways that dementia and people with dementia are perceived and portrayed, and reflecting on the ethical implications of this for people with dementia. The group, which was chaired by Dianne Gove from Alzheimer Europe, included participants from a wide range of backgrounds including old age psychiatry, psychology, dementia, philosophy, cultural sociology, nursing and media studies. One member of the group had dementia, one was a current carer and some had past experience as carers. Alzheimer Europe is extremely grateful to the members of the working group who are listed below in alphabetic order. Further details about the participants can be found in Appendix 1.

- Dr Debby Gerritsen, Radboud university medical center, Nijmegen (Netherlands)
- Ms Bénédicte Gombault, King Baudouin Foundation, Brussels (Belgium)
- Dr Dianne Gove, Alzheimer Europe (Luxembourg)
- Dr Fabrice Gzil, Fondation Médéric Alzheimer, Paris (France)
- Ms Jana Kasparkova, ICU in Teaching Hospital, Plsen and Faculty of Humanities, Charles University in Prague (Czech Republic)
- Prof. Jan Oyebode, Bradford Dementia Group, University of Bradford (UK)
- Ms Sirpa Pietikäinen, MEP (Finland)
- Dr Christine Swane, EGV Foundation, Copenhagen (Denmark)
- Associate Prof. Baldwin Van Gorp, KU Leuven (Belgium)
- Ms Aino Valtanen, Assistant to MEP (Finland)
- Rev. Richard Wallace (UK)
- Dr Daphne Wallace (UK)

A broad overview of the literature was made, drawing on a wide range of sources such as articles in peer reviewed journals (identified through a search of several scientific databases), publications, reports and other studies, personal accounts of people with dementia and media accounts. The sub-topics addressed were identified by means of chunk coding and group discussion. The various quotes have been included to provide a meaningful illustration of the way that dementia is portrayed and perceived. Overall, we have tried to demonstrate the diversity of perceptions and portrayals, rather than provide a summary of a kind of generalised overall perception/portrayal.

The working group met on two occasions in Brussels in 2013, each time for a full day's discussion and exchange of ideas covering the structure and content of the report. Members of the group also shared their expertise on various relevant issues, commented on the literature review, discussed the possible ethical implications of the issues addressed and contributed towards the development of the ethical recommendations/position. Various drafts of the text were circulated electronically and members of the group reworked the report and debated various issues until a consensus was eventually reached and the final text presented to the board of Alzheimer Europe for approval. The report was formally approved and adopted by the Board in December 2013.

## 2. *How dementia is perceived and portrayed*

### Explanatory models of dementia

People have been aware of dementia for as long as we have recorded history and many have tried to define and explain their perception of it. People with dementia have mainly suffered the consequences of such perceptions, although there has been a gradual movement towards respect of personhood and the development of person-centred approaches to dementia. However, disagreement over the cause and nature of dementia persists amongst lay people, professional carers, scientists and theorists. Beliefs that dementia is a natural part of ageing have persisted for thousands of years alongside other theories linked to mental disorders, brain disease, biology and, more recently, to lifestyles, theories incorporating the concepts of disability, personhood, psychology and the social environment. These are discussed in the following sections. Some of the ways that dementia is now perceived are grounded in official discourses from professional bodies, the state and NGOs and some were initially described by philosophers and theorists.



In the following sections, we will group together different explanatory models and follow each set by a consideration of the related ethical issues. The first set covers perceptions linked to the individual and to well-established and often conflicting perceptions of the nature and cause of dementia, namely:

- dementia as a part of the normal ageing process,
- dementia as a biomedical condition and
- dementia as a mental disorder.

#### ***A natural part of ageing/a disease of older people***

Dementia is frequently perceived as a condition affecting older people and as a natural part of ageing. Studies which have investigated the historical development of the concept of dementia and Alzheimer's disease (AD) (Berchtold and Cotman, 1998; Karenberg and Förstl, 2006) suggest that there has been recognition of a strong association between cognitive decline and ageing for well over a thousand years. Pythagoras, Hippocrates, Plato and Aristotle, for example, seem to have considered cognitive decline as an inevitable part of ageing, and Aristotle and Galen may have considered old age and the last stage of life as a diseased state rather than natural (Berchtold and Cotman, 1998). Cicero (ca. 150-200 AD), on the other hand, seems to have believed that "dotage" ("that foolishness which is associated with age") was not inevitable but typically associated with "old men of trivial character, not to all old men" (Karenberg and Förstl, 2006, p.7). Nevertheless, even though it is probably uncommon to consider old age in itself as a diseased state nowadays, beliefs about cognitive decline being a normal part of the ageing process have persisted, as demonstrated by the following statement from an older person.

*"But at the same time everybody has got to grow old and you're bound to lose your faculties as you get older. You can't help it really." (Corner and Bond, 2004, p.146)*

Scientific studies to-date support the association between dementia and ageing, demonstrating, for example, that the prevalence of dementia increases exponentially with age (ALCOVE, 2013; Alzheimer Europe, 2009; Ferri et al., 2005; Hofman et al., 1991; Plassman et

al., 2007). However, commenting on the results of the EuroCoDe meta-analysis of risk factors for dementia, Frölich (2008) concluded, "Although age is the most significant risk factor we know about, dementia is not an inevitable part of ageing" (p.132). Similarly, Kennard (2005) remarks "The strongest risk for Alzheimer's is age, but dementia is not an inevitable consequence of age nor does it only affect the elderly." Ballenger (2008) notes that there is a problem in viewing AD as being "an extreme point on the continuum of ageing" because there are well-documented cases of very old people exhibiting very little cognitive impairment. Studies involving large numbers of extremely old people (e.g. over 105) are lacking. Until sufficient numbers of the "old-old" can be assessed, the debate, which has spanned over a thousand years, will most likely continue.

Discussions within medical and scientific circles also continue (Scodellaro and Pin, 2013). The fact that AD is more common in older people does not prove that old age causes AD and some scientists are starting to question the usefulness of making any kind of link to the ageing process. There is also uncertainty amongst lay people and some healthcare professionals about the distinction between normal ageing and dementia. Some healthcare professionals have reported difficulty distinguishing between normal ageing, dementia and depression (Gove, 2012; Rolland-Dubreuil et al., 2003 – see also Keady, 1996).

Perceptions of dementia or severe memory problems as a natural part of ageing may be more common in some cultures at specific historical times. Chinese, Vietnamese and Filipino immigrants to the United States, participating in focus groups, expressed the belief that certain behaviour (typically considered a symptom of dementia) was a natural consequence of the ageing process (Braun and Browne, 1998). Similar findings have been reported in studies in Israel (Werner, 2004), and amongst people of South Asian origin in the UK (La Fontaine et al., 2007) and African Americans (Roberts et al., 2003). In their survey-based study involving four ethnic groups (193 subjects in total), Ayalon and Areán (2004) found that in contrast to the Anglo group, three ethnic groups (i.e. Asian, Latino and African-American) were more prone to consider AD part of normal ageing.

With regard to a possible link between dementia and normal ageing, Corner and Bond (2004) point out that there may be confusion about what the word "normal" means. Normal could be interpreted in the sense of normative/usual (meaning that something is fairly common or typical) or in the sense of non-pathological (meaning that something is not abnormal). Even a medical diagnosis of AD can be normalised in that people may interpret it as being the term for "normal memory loss as we get older" (Connell et al., 2007).

Even when dementia is recognised as a medical condition, some of the early symptoms are sometimes normalised (i.e. perceived as normal in view of the person's age) until they become more severe. There may be a threshold or cut-off point for people with dementia, or their relatives and friends, when the symptoms become so severe or out of the ordinary or, alternatively, are highlighted by outsiders or by critical events, that they can no longer be attributed to normal ageing (Keady and Nolan, 2003; Krull, 2005; Mahoney et al., 2005). This process may delay facing the prospect of dementia. Whether the process of normalisation is based on a lack of knowledge about dementia or a psychological process of denial is not entirely clear. Scodellaro and Pin (2013) report the findings of a French study by Rozotte (2003) in which despite a diagnosis of AD, problems were described in terms of "senility" and "softening of the brain" (*ramollissement cérébral*), both of which were considered as part of the normal process of ageing.

In contrast, a sample of 856 older people in Turkey (aged 70 or over, without dementia), considered dementia occurring in old age as a normal phenomenon but did not consider the symptoms typically associated with dementia as being normal. Significantly fewer women considered dementia a normal part of ageing or the symptoms as being normal and they were more likely to seek medical advice, whereas age and education did not significantly affect perceptions.

Some people attribute dementia to the ageing process and at the same time to other factors (Ayalon and Areán, 2004; Lee et al., 2010). For example, in Ayalon and Areán (2004)'s study referred to above, they noted that the Asian, Latino and African-American participants perceived dementia as part of normal ageing but also contagious and a form of insanity. The authors suggest that whilst these three views may seem contradictory, it is possible that normalisation occurs in the early stages and that beliefs about insanity as well as contagion are more prominent as AD symptoms become more severe and more obvious.

Finally, dementia is a condition which many people believe only affects older people (i.e. typically over the age of 60 or 65). This is perhaps understandable as the vast majority of people with dementia are older.

*"I think they associate Alzheimer's with 85-year-olds."*

*"I think they think it's for old people. They say to me, "You're too young"."*

*(both quotes from Devlin et al., 2007, p.52)*

Such perceptions can even be found amongst service providers as the following extract about Dave (a man with early onset dementia) demonstrates.

*"The manager thought that Dave was a carer. Dave played along, not disclosing his diagnosis. The manager asked an older carer who had been sitting quietly: "When did you receive your diagnosis?" At this point, Dave admitted that he was the one they would eventually be looking after." (Chaston, 2010, p. 223)*

### **A biomedical condition**

Dementia is sometimes perceived in predominantly biomedical terms with a focus on neuropathology in the brain (Cummings, 2007; Gaines and Whitehouse, 2006; Katzman et al., 1978). The features of AD have been described as including "neuronal loss, neurofibrillary tangles, neuritic plaques and amyloid angiopathy..." (Cummings, 2007, p.3). In 1970, based on extensive work on postmortem brains, Tomlinson, Blessed and Roth (the Newcastle group) claimed that they could demonstrate the difference in pathology between the brains of people with dementia and those without. They also correlated plaques in the brain with scores on standardised dementia scales (Ballenger, 2008). From the 1970s onwards, numerous advances were made in the fields of genetics, neurochemistry, biochemistry, molecular science and epidemiology which all contributed to a better understanding of the neurochemical, neuropathic and genetic aspects of AD. These developments together contributed towards the acceptance of a biomedical model of dementia as the standard paradigm for dementia which means that this became the standard theoretical framework for scientific thinking and practice and was widely accepted as the way to perceive and make sense of dementia. The biomedical approach has dominated perceptions of dementia for decades.

Despite these recent biomedical developments, there is a view that the biomedical model is not entirely sufficient in explaining dementia. The Medical Research Council/MRC CFAS (2001) found insufficient difference between the brains of people over the age of 80 and 90 with and without dementia solely in terms of neuropathology. Moreover, as Ballenger (2006) points out, statistical correlations between the presence of plaques and scores on psychological tests, as demonstrated by the Newcastle group, do not necessarily infer causation. The European Federation of Neurological Societies stated in its guidelines that with the remarkable exception of autosomal dominant causes of dementia, there is no specific biological marker for degenerative dementias and that the aetiological diagnosis of dementias could only be made in terms of probability (Waldemar et al., 2007).

Kitwood (1997) suggested that it is impossible to have purely organic mental disorders, clearly demarcated from those which are not. Similarly, White, Rickards and Zeman (2012) cite several meta-analyses which suggest that structural brain abnormalities are present in a number of “non-organic” mental disorders such as schizophrenia, bipolar affective disorder and obsessive-compulsive disorder and suggest that the mind is indivisible from the brain. Nevertheless, at the current time in Europe, emphasis on the organic nature of dementia creates a distinction between dementia and many other mental disorders, whilst its impact on cognitive and mental health equally separates it from most other physical health conditions. The distinction being made in this report between mental disorders and biomedical conditions should be interpreted as a reflection of the way that dementia is sometimes perceived and not as recognition of the validity of making such a division.

### ***A mental disorder***

For centuries there was no common term for dementia and some of the earlier accounts of cognitive decline in old age may have been broader than the current definition of dementia. From the 16th century onwards, there was an increasing interest in mental disorders and a classification of different conditions, as well as a greater acceptance of dissection of the human body which led to an increased interest in anatomical differences in the brain (e.g. colour, size, texture, humidity etc.) (Berchtold and Cotman, 1998), which is also relevant to the preceding section on dementia as a biomedical condition. In 1907, Alzheimer described the neuropathological features of what came to be known as Alzheimer’s disease (AD).

Although AD was described in DSM-IV as an organic brain disorder, characterised by a distinct neuropathology in the brain, DSM is the abbreviation for the Diagnostic and Statistical Manual of Mental Disorders and was produced by the American Psychiatric Association so the link to mental disorder, or at least to the fact that people with possible dementia are referred to mental health services, is clear. In the revised version of the above-mentioned manual (DSM-V), dementia can be found in the category “neurocognitive disorders”, in the sub-section “major and mild neurocognitive disorders”. Various types of dementia are described with specific reference to each specific disease (e.g. major or mild neurocognitive disorder (NCD) due to Alzheimer’s disease, NCD due to Parkinson’s disease etc.). This is separate from other mental disorders which can be found in sections such as “schizophrenia spectrum and other psychotic disorders”, “bipolar and related disorders” and “depressive disorders” etc. The term “dementia” is nevertheless retained in DSM-V for continuity and can still be used but the term NCD may be preferred for conditions affecting younger people (American Psychiatric Association, 2012). NCT is also a broader term than dementia



as it may cover conditions for which there is significant decline in a single area (e.g. amnesic disorder). Nowadays, many people consider dementia as a mental disorder with all the negative associations that this may entail whereas others differentiate between dementia and mental illness. In some cases, this may result in people finding a diagnosis of dementia (or a named form of dementia) reassuring in that it confirms that they are not “going mad”.

*Life can be depressing enough, but if you are not given the diagnosis, you may well worry that you are going mad. (posted on Talking Point, 2006, cited in Alzheimer's Society, 2008 [Literature review of “Out of the Shadows”]).*

In the “Facing Dementia Survey”, 19% of the 600 lay people interviewed associated dementia with being crazy or insane compared to just 4% for AD. This suggests confusion about the meanings of the two terms (Rimmer et al., 2005) because as AD is a form of dementia, people who associate dementia with mental illness, should also associate AD with mental illness. This also demonstrates the importance of the meanings attached to words.

As many people consider dementia as a mental disorder, it is important to look at the way that people with mental disorders are perceived and treated. Many people with dementia and their relatives are concerned about dementia being considered a mental disorder, as the following carer explains:

*“When the [appointment] letter arrived and it said on it “mental health” you didn’t want to know because I think that perhaps people of our generation, there is stigma to mental health. Mental health means insanity.” (Alzheimer's Society, 2008, p. 47)*

People with mental illnesses are also frequently perceived by the general public as being recognisably different, dangerous and unpredictable (Angermeyer and Matschinger, 2004; Lauber et al., 2006; Pescosolido et al. 1999; Thornicroft, 2006). This perceived dangerousness has been found to be associated with negative emotions and discriminatory behaviour (Angermeyer and Matschinger, 2004; Corrigan, 2007; Markham, 2003; Stanculescu et al., 2009; Thornicroft, 2006). People with dementia do not, however, seem to be perceived as being physically threatening even though they are sometimes perceived as being verbally or physically aggressive. Please see section on stereotypes of dementia.

In the past, people with mental disorders were often removed from the community and placed in mental institutions and asylums. Perhaps one of the most famous asylums was the Bethlem hospital in London (commonly known as Bedlem), established in 1247, where people were kept in chains in appalling conditions (Hinshaw, 2007). A more humane approach gradually developed, mainly as a result of changes implemented by Pinel in France at the beginning of the 19th century, but for a long time this was not the norm. Nowadays, conditions in most countries have greatly improved and many people with mental disorders live independently within the community. Nevertheless, there are reports that the human rights of people with mental disorders are still not always respected (Hemmens et al., 2002; MDAC and SHINE, 2011; Vaswani, 2013).

Mental disorders are also perceived as resulting in discrimination, which is a key component of stigma. A combination of self-reports, historical accounts and statistics (e.g. from government sources and advocacy groups) attest to discrimination against people with mental disorders in the fields of health care, employment and education (Crowther et al., 2001; Mataityte-Dirziene and Sumskiene, 2009; Wahl, 1999) as well as social distancing

(Angermeyer and Matchinger, 2004 & 2005), and being subjected to inhumane treatment in some societies (Diatri and Minas, 2009; Doloksaribu, 2009; Vaswani, 2013). Similar forms of discrimination against people with dementia have been reported.

### Related ethical issues

#### *Equity*

The perception and portrayal of dementia as part of the normal ageing process, a biomedical condition or a mental disorder may contribute, in different ways, towards people with dementia not having the same access to appropriate care and treatment as that provided to other members of society.

Attributing cognitive decline to normal ageing, for example, emphasises its non-pathological nature and the fact that it is incurable (based on the belief that ageing is inevitable and unstoppable). This may result in people delaying or failing to consult a doctor and consequently, not accessing the support and treatment to which they are entitled. Whilst AD is incurable, the 1990s marked the arrival of drugs to ameliorate the overall symptoms. Pharmacological treatment does not exist for all forms of dementia and is not effective for everyone who takes it but a precise diagnosis is needed in order to give those who might benefit from it the opportunity to do so. Timely diagnosis is not only linked to access to treatment but also to other factors such as being able to make an advance directive, plan one's life and care, come to terms with the prognosis and avoid crises (Woods et al., 2003).

Younger people with dementia are also at risk of experiencing inequity with regard to care and treatment due to some healthcare professionals being unaware of dementia in this age group (Chaston, 2010). This may result in younger people not obtaining a timely diagnosis. If and when diagnosed, they may have limited access to appropriate services and support as these were designed with other groups in mind (e.g. people with disabilities, people with mental disorders and older people), as well as to healthcare professionals who are aware of dementia in the younger population. Failure to obtain a timely diagnosis in people with dementia of working age may result in difficulties at work and, due to ignorance of their condition, to unfair dismissal (i.e. for professional incompetence as opposed to mental incapacity). This may have disastrous effects on their financial situation, their future pension rights, their self-esteem and their relationships (Bakker et al., 2013a & 2013b; van Vliet et al., 2013).

In contrast to the perception of dementia as part of normal ageing, the perception of dementia as a biomedical condition may motivate people to seek a diagnosis, and legitimise expectations for the care and treatment of those affected. However, the over-medicalisation of dementia may result in a focus on treatment and the quest for a cure, with the subsequent underdevelopment of appropriate social support for people with dementia and their carers (Swane, 1996). It may also limit flexibility and creativity in considering possible alternative ways to address issues related to the care of people with dementia (Whitehouse, 2013). Failure to recognise the social aspects of dementia may result in the lack of comprehensive, coordinated care, particularly in countries where health care and social care are managed by separate bodies and where neither body fully accepts responsibility for the care and support of people with dementia. An awareness or belief by the general public that there is insufficient care for people with dementia, combined with knowledge that there is as yet no cure, may result in a lack of motivation to seek a diagnosis.

The term “senility”, which is not widely used nowadays, represented for many people a mixture of elements of a “natural ageing process” and of a mental disorder, and was also used in the medical domain. Butler noted that in lumping together treatable and reversible conditions along with irreversible brain damage, “the elderly often did not receive the benefits of decent diagnosis and treatment” (Butler, 1975, pp.9-10, cited in Ballenger, 2008).

Inequity in the domain of healthcare based on age may be experienced by older people with dementia and this can sometimes be very subtle. For example, it could involve prioritising care or allocating resources to other age-groups, withholding expensive medical treatment from very old people (for reasons which cannot be justified on medical grounds alone), and not giving older people the same amount or quality of information etc. (Kane, 2002), limiting consultation times to one problem or ten minutes even though older people are more likely to have complex medical conditions, addressing older people in an over-simplified and patronising tone (Caporael et al., 1983; Montepare et al., 1992) or not giving due attention to serious thoughts, feelings and concerns expressed by older people (Grainger et al., 1990 in Nelson, 2002).

The classification of dementia as a mental disorder may sometimes result in people with dementia being offered inappropriate services which do not correspond to their specific needs (e.g. being admitted into a psychiatric hospital or ward which is not an ideal setting for the care of people with dementia). It is essential for the development of appropriate services to focus on dementia in its own right rather than in the global context of mental disorders. On the other hand, failing to perceive and hence categorise dementia as a mental disorder may in some countries deprive people with dementia of the expertise and psychiatric support provided by psychiatrists to people with other mental disorders. In France, for example, the focus on the organic aspects of AD may have contributed towards it being considered a matter for neurologists and not psychiatrists (Ngatcha-Ribert, 2004). There, psychiatrists have a fairly limited role in the care and treatment of people with dementia, other than in connection with “behavioural and psychological symptoms of dementia”. It is possible that in some countries, where dementia falls outside the general remit of psychiatry, people with dementia do not receive the benefits which might accrue from psychiatric expertise and support which is often more holistic than neurological care.

The issue of equity can also be considered in relation to the distribution of research funds. Ballenger (2006) argues that whereas an emphasis on dementia as a natural part of ageing may have delayed valuable research into the causes of dementia and a possible cure, research into AD has become ideologically driven, based on the biomedical model, in that applications for funding based on hypotheses reflecting a perception of dementia as a natural part of ageing may be hard to defend. The focus on biomedical explanations of dementia may have also contributed towards an imbalance in the distribution of funds for biomedical research into treatment or cure, as opposed to psycho-social research, especially in relation to care issues. Even within the context of biomedical research, as AD is commonly associated with older people and as the greying of the population is frequently discussed in alarmist terms, it is possible that other forms of dementia (e.g. where there is a clearer association with other factors such as alcohol consumption or the cardiovascular system) receive less funding for research.

## Stigma

The belief that dementia is a natural part of ageing or only affects older people may contribute towards the stigmatization of people with dementia on the basis of age (i.e. ageism). In addition, there is widespread stigmatization of people with mental disorders or “mental health” problems (Angermeyer and Matchinger, 2004; Corrigan, Kerr and Knudsen, 2005; Hinshaw, 2007; Thornicroft, 2006). Schizophrenia is often taken as a paradigm for all mental disorders with the result that a wide range of very different mental disorders are considered as having the same effects and are stigmatized in the same way (Thornicroft, 2006). The association between dementia and mental disorders may therefore also contribute towards stigma.

The term “age-ism” was originally coined by Butler (1975) who described it as “uneasiness” or “distaste” for growing old and “a process of systematic stereotyping of and discrimination against people because they are old” (Dobbs, Eckert and Rubinstein, 2008; Widrick and Raskin, 2010). He likened such negative attitudes and behaviour towards older people to sexism and racism and believed that ageism could be detected, for example, in stereotypes, myths, disdain, demeaning jokes and discriminatory practices (Ballenger, 2006). Ageing and ageism have been identified as possible factors contributing towards the stigmatization of people with Alzheimer’s disease but also as forms of co-existing stigma (Chan and Chan, 2008; Clarke 2005; Iliffe et al., 2005; Stratton and Tadd, 2005) based on further categorisation of the people who have dementia. The following quote suggests a perceived hierarchy of devaluation with regard to age and dementia.

*“When you’re old, you’re on the scrap-heap, or at least you feel as if you are, that is people make you feel as if you are. I suppose I think that the people who have Alzheimer’s and dementia are at the bottom of the scrap heap, and ... most people would just think they should die.” (Corner and Bond, 2004, pp. 148)*

Graham et al. (2003) highlight the double jeopardy of older people with mental illness and the triple jeopardy of older women with mental illness (Graham et al., 2003), combining gender, age and mental disorder. A healthcare professional described double stigma as follows:

*“Yeah it’s a double whammy isn’t it where they’re both victims of ageist attitudes by virtue of their growing old and then victims of you know negative attitudes by virtue of their having what might be considered a kind of mental health problem and a very stigmatising problem, so the two intersect resulting in their being very ostracised oftentimes by society.” (Nolan et al., 2006, p.77)*

Whilst old age is not associated uniquely with negative characteristics (Fiske et al., 2002), ageism is constructed around negative stereotypes of older people which highlight physical and cognitive decline, as well as interpersonal deficiencies (Montepare and Zebrowitz, 2002 in Heatherton et al., 2003). Several ageist stereotypes have been found in the literature, which include older people being unproductive, disagreeable, dependent, vulnerable, fragile, irritable, boring, grumpy, weak, mournful, debilitated, needy and cognitively impaired (reported in Coudin and Alexopolous, 2010; Scholl and Sabat, 2008; Widrick and Raskin, 2010). The blurring of the boundaries between negative perceptions of ageing and dementia may further contribute towards the devaluation of people with dementia, which is itself part of the process of stigmatization (Link and Phelan, 2001; 2006).

### *Wellbeing and social inclusion*

In contrast to concerns about ageism, Downs, Small and Froggatt (2006) argue, in the context of palliative care, that associating dementia with normal ageing may have a positive outcome. Liu et al. (2008) also suggest that the normalisation of dementia within the Asian American community might result in less stigma. When behaviour, which would otherwise be attributed to dementia, is perceived as “normal”, the person with dementia is not considered as a patient or a “victim” but as a valued older person. Their place within the family is not adversely affected. A similar effect might occur as a result of the disavowal of “deviance”. According to Davis (1961), this occurs when interactions between people with an obvious impairment and others are rendered less awkward as a result of drawing attention to the impairment in a matter of fact way. On the other hand, specific needs linked to the symptoms of dementia might not be adequately addressed if dementia is not recognised as a medical condition and people with dementia would therefore risk receiving sub-optimal or inappropriate care. Also, their valued place and identity is dependent on older people being valued within a particular community or society, and this is often not the case.

### *Fear*

The risk of dementia does increase exponentially with age and people may therefore increasingly fear developing dementia as they grow older. Fear is a factor which contributes to various attributes being perceived as stigmas (Jones et al., 1984; Stangor and Crandall, 2003). However, potential fear of dementia is not based solely on an awareness of the probability of developing it (e.g. based on age-specific prevalence rates or other factors such as genetic predisposition or having certain risk factors) as people attach varying degrees of importance to, and interpret the significance of, probability differently (Leibowitz, 1999). It is also based on how people perceive dementia and whether their perception of dementia is unpleasant or disturbing.

People may also have fears about ageing alongside the fear of dementia. According to Martens et al. (2005), there are three main fears linked to ageing. The first is the fear of death. The second is “animality”, a term used to describe the consequences of the deterioration of the physical body. The third is “insignificance” which is the term used to describe loss of self-worth due to various factors such as declining mental agility, physical beauty, productivity, strength and competence to name but a few. Martens et al. (2005) conclude that older people may trigger fears about losing the means by which one holds on to a symbolic sense of self-worth which they claim is a major protection against fears of mortality. As dementia tends to involve a gradual deterioration of both physical and cognitive abilities, combined often with fears about a loss of “self”, older people with dementia might easily be experienced as even more threatening due to the perceived combination of age-related and dementia-related deterioration.

### *Devaluation versus acceptability/respectability*

The focus of the biomedical explanatory model of dementia on damage to the brain may serve to distinguish dementia from other mental disorders and from the normal ageing process, thereby giving it a certain degree of “respectability” and making it more acceptable. Terry Pratchett, a famous British fiction writer who has a rare form of AD, emphasised the importance of the brain when he stated, “In too many people’s minds Alzheimer’s is considered madness. It is a physical disease that affects the brain” (Pratchett, 2009). How-

ever, in some cultures, such as La Réunion, linking a medical condition to the brain creates a link to madness so perceiving dementia in biomedical terms linked to the brain would not be helpful (Enjolras, 2005; Scodellaro and Pin, 2013). Compared to perceptions of dementia as normal ageing and to the vague concept of “senility”, having a recognised medical condition (such as Alzheimer’s disease, dementia with Lewy bodies and Pick’s disease) may nevertheless enable people to consider themselves as patients who have the same rights and deserve the same respect as those with any other condition, which is also an issue of equity. Nevertheless, Ngatcha-Ribert (p.27) comments that “it is astonishing that in our society the status of being “sick/ill” is preferred in a certain manner to that of being “old”, the latter being suspected of also being senile”.

#### *Losing sight of the person with dementia*

Sabat (2008) suggests that perceiving dementia as the outcome of brain damage and subsequently, most symptoms as being the outcome of neuropathology caused by the disease process, leads to an approach which focuses on “managing the patient” often by means of drugs (i.e. through chemical restraint). The same perception might be used to justify the use of other forms of restraint, none of which can be considered as being in the best interests or ethically justifiable for people with dementia (Alzheimer Europe, 2012). According to Girard and Ross (2005), in the biomedical model of dementia, life and disease are interpreted in a mechanistic manner, whereby the social reality or meaning of dementia, as well as social and psychological processes are excluded. Yet what pathologists can see in the brain cannot directly explain behaviour and the same applies vice versa.

Perceptions of dementia as a biomedical issue may be accompanied by the perception of scientists and healthcare professionals as having a monopoly on knowledge and as being the experts in dementia. The perspectives of people with dementia may be perceived as less important and less relevant (i.e. as they do not have the knowledge or awareness of what is going on in their “damaged brains”). The psychological, emotional and social impact of dementia on people with dementia and on their carers is thus neglected. In some cases, experiences reported by people with dementia, which do not correspond to the established biomedical explanation for dementia, may even be challenged, and the accuracy of their diagnosis questioned, as it is the medical experts who define dementia and the validity of the experience of people who actually have dementia is not recognised (EWGPWD, 2012).

#### *Personhood/the status of being a person*

Emphasising the biomedical aspects of dementia has implications for personhood. There is a risk of losing track of the individual who has dementia and of attributing emotions, motivation and behaviour to damage in the brain. According to Gubrium, (1986), “Even normal behaviour is interpreted in terms of disease stages”. People with dementia are reduced to their neurobiology or neuropsychology with the result that the psychosocial factors are neglected (Cotrell and Schulz, 1993; Lyman, 1989). This may have a negative impact on the person’s care but also on wellbeing and self-esteem as it denies each person with dementia the right to be considered as a unique individual and to exercise autonomy through their acts and speech. It disempowers people with dementia by rendering their acts and speech meaningless and may lead to a vicious circle of frustration and seemingly inappropriate behaviour. Sabat (2008) suggests that often, in the light of their experience and the way they are sometimes treated with an emphasis on perceived deficits, it is normal for a

person with dementia to react with anger, withdrawal or depression and that failure to do so might even justify the assumption that they lacked insight or were “blissfully unaware”.

The medical model of dementia and the emphasis on dementia as an organic brain disorder may serve to detract attention from the person as a whole onto the brain of the person. According to Chaston and Bender (1999) this may help people deal with the emotional threat of dementia (i.e. the thought that “it could be me”), may create a distance from the human tragedy involved and lead to the adoption of defences such as denial and depersonalization whereby the person with dementia is perceived as having no insight and being a non-person.

#### *Recognition of autonomy/responsibility for one's actions*

Dupuis et al. (2012) suggest that the dominant biomedical perception of dementia pathologises the behaviour of people with dementia leading to it being perceived as deviant and needing to be managed (which often implies managing the person with dementia), and to the person being labelled on the basis of their behaviour. Downs et al. (2006) use the term “diagnostic overshadowing” to describe the way that all actions and expressions come to be attributed to the labelled condition. Similarly, the perception of dementia as a mental disorder may lead to a tendency to use terms such as BPSD to describe behaviour which might otherwise be interpreted in a different light, and consequently to use drug-related responses to such behaviour which were developed in the field of psychiatry. Dupuis et al. (2012) suggest the need for a “responsive behaviour discourse” which views all actions as meaningful and moves from judging behaviours to understanding meaning in actions and responses. This also involves moving away from a focus on dysfunction, deficit and decline and away from assessing, correcting and controlling perceived “problems” within the person. They stress the importance of looking beyond the individual to reflect on the broader social and physical environment.

On the other hand, perceiving the brain as the cause of behaviour which is perceived as challenging may help carers to deal with it more positively as the person with dementia is not considered as being deliberately obstructive or nasty. However, this can also be damaging as carers may overlook a range of other factors which are contributing towards the behaviour that they find challenging and which are amenable to change.

For professional care staff, the issue of whether a person with dementia is responsible for his/her behaviour can also be important (i.e. can the behaviour be attributed to the person having dementia or was it carried out with awareness and intention?). The belief that behaviour, which is deemed inappropriate, is not intentional may, for example, result in a more understanding and tolerant reaction towards the person concerned and is therefore relevant to the wellbeing of the person with dementia. The following statement was made, in the context of a qualitative study, by a staff member in a long-term care facility for people with and without dementia.

*“I think it depends, for me it depends on whether I think they can help it. If, you know, I would certainly feel differently if it was a cognitively well person groping at me than I feel about [someone else].” (Dupuis et al., 2012, p.167)*

Tolerance of behaviour by people with dementia, which is considered inappropriate or disturbing, demonstrates a humane and understanding approach to people with dementia. However, even if unintentional, some behaviour may lead to distress amongst care staff

and informal carers by threatening their physical or mental integrity. The fact that a person with dementia is unaware of the inappropriate or disturbing nature of certain behaviour should not justify its continued occurrence as the wellbeing of all residents or cohabitants, as well as staff, must be taken into consideration. In addition, not all behaviour exhibited by a person with dementia can necessarily be attributed to dementia. Doing so might be considered as a very narrow biomedical approach, reducing people with dementia solely to their brain damage and freeing them from all social and civil responsibility.

In the context of defining relationships between people with dementia and paid carers, Müller-Hergl (2004) suggests that it may sometimes be constructive to consider certain acts as intentional. Taking the example of smearing and handling faeces, he highlights the conflicting position of the carer as a powerful helper but also as vulnerable and powerless “in the face of extreme strangeness”, and suggests that it may be helpful to understand such behaviour as a message, reaction to under-stimulation or neglect, and the awareness of unequal power relations, a protest against “social death” and a radical show of autonomy. In this sense, perceiving the behaviour as a consequence of damage to the brain would not be helpful.

Other researchers and psychologists have also emphasised the importance of searching for possible meaning in the behaviour of people with dementia (e.g. Dröes, Manthorpe, Moniz-Cook, Stokes and Swane), particularly with regard to adaptive tasks such as trying to cope with disabilities, preserve emotional balance and a positive self-image and prepare for an uncertain future (Dröes et al., 2011). However, in attributing complex psychological and emotional motives to the behaviour of people with advanced dementia who are unable to express themselves verbally, there may sometimes be a risk of over-interpretation, projection and inappropriate re-framing which may be detrimental to the wellbeing, quality of life and continued care of that person. In the context of a study carried out in the Czech Republic, several nurses working in the hospital setting suggested that behaviour which they find challenging may result in patients with dementia being neglected (Kasparkova, 2009).

#### *Loss of freedom*

The classification of dementia as a mental disorder may have implications for the restriction of freedom of people with dementia. Having a mental disorder is one of the necessary legal conditions to involuntarily detain a person for their own safety or that of other people even though, in most countries, there is no direct reference to dementia. Usually, the places in which a person can be detained are mental institutions which are not appropriate for the care of people with dementia. The lack of appropriate legislation covering the involuntary stay of people with dementia in nursing homes and their having to attend or move into closed day care centres and nursing homes against their will may represent discrimination against them and a failure to respect their fundamental human right to freedom. The lack of services specifically designed for the specific needs of people with dementia may further contribute towards the unfair restriction of their freedom because they would have the freedom to live in their own homes if appropriate services and support were available.





The above ways of making sense of dementia, particularly as being linked to a developmental/ageing process or to biomedical factors, is further linked to three other ways of making sense of dementia, namely,

- as a second childhood
- as a hereditary/genetically-determined condition or
- as a contagious condition

### ***A second childhood***

Descriptions can be found dating back more than 2,500 years which portray older adults as becoming children once again. Whilst direct reference is not made to dementia, as this term did not come into being until much later, such sayings can most probably be understood as referring to people who nowadays are considered as having dementia. The following quotes are taken from Harry Cayton's 2001 presentation "From Childhood to Childhood":

- Men are children twice over (the Greek playwright Aristophanes)
- They say an old man is twice a child (Shakespeare, in Hamlet)
- The life of man is a circle from childhood to childhood (19th century Sioux shaman, Black Elk)

Such descriptions could be considered as the individual perceptions of the playwrights and the shaman quoted. However, references to people with dementia being like children or in their second childhood are still fairly common in today's society. As with the perception of dementia as a natural part of ageing, there is often a hint in references to dementia as a "second childhood" of this being in some way a "natural state". The perception of people with dementia being like children can sometimes be detected in behaviour such as infantilization (Kitwood, 1997) and "secondary" or "displaced" baby talk which involves the use of a high pitch and exaggerated intonation (Caporael et al., 1983).

Relationships are complex and different people mean different things by the terms "child" and "childhood". Some may have in mind a baby or infant, others a toddler and others, people under the age of 16 or 18. Perceiving dementia as a second childhood not only positions the person with dementia in the role of the child but often involves other people positioning themselves as parents (i.e. role reversal). People with dementia do not necessarily accept such positioning and may still feel that they are looking out for their children, even if the latter are unaware of this or feel that the opposite is the case, and this might actually reflect a meaningful, positive, reciprocal relationship of care. In one study (Tunnally, 2002), older women and their caregiving daughters were interviewed about their relationship. It was found that the adult-children assumed power over their parents, adopting a paternalistic attitude as part of a perceived role reversal. The parents handed over power to their children as a repayment for care but did not perceive roles to have reversed, and indeed, still looked out for their children's welfare.

People with dementia may sometimes feel infantilised as a result of guardianship arrangements or moving into one of their children's homes even though others do not perceive them in this way. Often, it is the perceived behaviour and dependency of people with dementia which leads other to the association with childhood. However, Cayton argues that even if some of the functional and affective behaviours of people with dementia may seem quite similar to those of children, the underlying neurological processes are totally

different. An anti-stigma campaign provided the following vignette in which the perception and portrayal of people with dementia as children was challenged:

*“Dementia is a devastating disease. It robs you of all your faculties. They say it is like a second childhood. But it isn’t. A child is a developing person. A man with dementia is a disintegrating person. He was a man. He lived alone. He had a family, a wife, children. He was gay. He was black. He was white. He was a successful businessman. He was someone who didn’t do what he wanted. He spent his adult life getting washed, dressed, going to the toilet, shaving, eating. He could speak. He could laugh at a joke. He could look after himself. Now, bit by bit he slides into dependence. It is not child-like. The infant takes her care for granted. He fights against his. The baby loves having her nappy changed. His incontinence pad shames him. The toddler gladly takes the other’s hand. He cannot abide being led from place to place. Or if he can, you cannot bear to see it. ....” (Crisp, 2009).*

It is interesting to note in the above citation that in arguing against the description of people with dementia as being in their second childhood or childlike, the author describes a person with dementia as a “disintegrating person”, slipping reluctantly and even with shame into dependency as opposed to enjoying the emotional bond that being cared for might provide. This highlights the complexity of the way that dementia is perceived and portrayed and that the impact or implications of the language we use is not always clear. The media has also played a role in suggesting similarities with infants or children through the portrayal of emotional regression and economic dependency of people with dementia (Ngatcha-Ribert, 2004).

In recent years, some healthcare professionals have linked the theory of a return to childhood/infancy to research in child development (e.g. to the model of child development proposed by the French psychologist Jean Piaget). Dr Barry Reisberg, for example, who described different stages of AD, also produced a comparative table of these stages in which certain behaviours typically associated with child development are presented in reverse order (i.e. people with dementia are portrayed as losing the skills that children are acquiring). In this table, “control of bowels” and “control of urine” are linked to 2-3 years and 3-4½ years of age respectively for children and stage 6 for people with AD (Cayton, 2001). Commenting on Reisberg’s table, Cayton points out that AD is not “normal” development even in reverse and that the inevitable loss of function that it entails is not comparable to the acquisition of new skills which is an inevitable part of growing up.

### ***A hereditary condition***

Perceptions of dementia being in some way a biomedical condition (or partly due to biomedical factors as in the bio-psycho-social model of dementia) are accompanied by the notion that some forms of dementia can be inherited. This perception is supported by research and is widely accepted within the scientific community. However, there are only a few thousand families worldwide for whom descendants who inherit a particular gene are practically certain to develop AD. Genes have also been linked to an increased likelihood of developing AD (i.e. a person with a particular variant of a gene or a combination of variants is considered as having a higher or lower risk of developing AD or of developing it a particular age). Nevertheless, there is no single gene responsible for all cases of Alzheimer’s disease and everyone carries some risk of developing the disease.

### ***A contagious condition***

The term “contagious” has now been widely replaced by communicable and means transmissible from one human or animal to another. There is one form of dementia (Creutzfeldt-Jakob disease) that is communicable. In the 1990s there were concerns that a new variant of Creutzfeldt-Jakob disease (vCJD) was due to contamination via consumption of beef from cows with bovine spongiform encephalopathy (BSE), also known as “mad cow disease”. According to the National Institute of Neurological Disorders and Stroke (2013), although laboratory tests showed that the prions in cows with BSE and those in vCJD were very similar, there was no evidence to prove transmission through beef. Nevertheless, an information sheet from Public Health England (an Executive Agency of the Department of Health) states that “many people in the UK were exposed to BSE because they ate beef and beef products from cattle that were infected with BSE” which also includes advice for people who have been identified as being at increased risk of CJD on how to reduce the risk of spreading CJD to other people (PBA, 2013, p. 2). It has been established that various forms of CJD can be transmitted through medical treatment including blood transfusion, surgery and treatment with contaminated hormones. Therefore, it is possible that some people have taken information about its communicability as being applicable to other forms of dementia, which are not communicable.

Perceptions of dementia as a contagious condition have been found to be more common in some cultures than in others. In a survey-based study in the United Kingdom, Purandare et al. (2007) found that a significantly higher percentage of South Asians perceived dementia as contagious compared to their Caucasian counterparts. Differences have also been observed amongst people from the same ethnic group in different geographical areas. For example, Asians<sup>1</sup> and Latinos scored higher regarding the perception of dementia as contagious in a survey of four ethnic groups in America (Ayalon and Aréan, 2004). By contrast, 91.3% of 209 Korean American immigrants responded in a questionnaire that AD was not contagious (Lee, Lee and Diwan, 2010). In the study by Ayalon and Aréan (2004), beliefs related to AD being both contagious and curable were recorded but it is not known from the published account whether the same people within the groups held both beliefs.

### **Related ethical issues**

The ethical implications of perceiving people with dementia either as having returned to the state of a child or as having a condition which is genetically determined or contagious can be positive or negative. They depend, for example, on how people perceive childhood and the place of children in society, and on people’s understanding of genetics, probability and communicability.

### ***Dignity, wellbeing and social inclusion***

The portrayal of dementia as a return to childhood by some leading healthcare professionals and its “grounding” in psychological theories of development, may lead to some people considering this a quasi-scientific “fact”. This may reinforce or serve to justify certain attitudes and care practices, such as infantilization and ignorance, which are demeaning and hence detrimental to the dignity and wellbeing of people with dementia. Cayton (2001) comments,

<sup>1</sup> It should be noted that descriptions of ethnic groups are not always comparable from one country to the next. For example, the term “Asian” tends to include people of Indian descent in the UK but less so in the USA.

*“Reisberg’s table seems to me to illustrate Kitwood’s “malignant social psychology”, seeing the symptoms of dementia as an inevitable, medically determined decline and reinforcing that decline by our response to it. In fact, self-care, continence, mobility and communication are we know all amenable to intervention even to improvement with the right care and environment” (Cayton, 2001, p.20).*

However, the implications of comparing a person with dementia to a child depend on a person’s beliefs about how children are or should be treated and considered. Such statements could be interpreted as being derogatory or patronising, attributing little value to the person’s opinions and wishes, and emphasising dependency. They might alternatively reflect sensitivity to the perceived needs and capacities of the person with dementia, recognition of the need for tolerance towards him/her, a desire to provide support and an appropriate level of protection or to foster independence to the extent that this is possible. On the other hand, the transition to adulthood is often accompanied by increased responsibilities and social status. Consequently, regardless of the intention, it may be disturbing for a person to feel that s/he is considered as a child. Even if the person with dementia has difficulty communicating, s/he may detect a tone of voice and gestures which indicate that s/he is not considered an adult. Being considered as a child (which the person is not) and not as an adult (which the person is) may contribute towards decreased self-esteem and social exclusion, particularly if the person is no longer considered an equal or as sharing common interests with other adults in his/her entourage.

The knowledge that some people with dementia have a gene variant which means that they will or are very likely to develop AD may lead to groups of people with those genes being considered as or feeling in some way inferior (e.g. as a kind of sub-group with a “defect”). This would have implications for their well-being and dignity and could contribute towards stigma, involving devaluation and social distancing. There are several national laws with Europe, as well as European and international regulations, which address genetic testing and describe their purpose as being to protect dignity, integrity, personality, self-determination and the inherent rights of human beings (Soini, 2012).

Alternatively, such perceptions could result in empathy towards people with dementia (as has been demonstrated recently in the media in connection with women who have specific inherited mutations in the genes BRCA1 and BRCA2 associated with an increased risk of breast cancer). The knowledge of one’s genetic status could be considered as being potentially empowering in terms of being able to take important decisions in an informed manner. On the other hand, this raises the issue of the right to know but also to not know, the risk of finding out without there being appropriate genetic counseling and of the knowledge causing anxiety, and the implications for relatives of such information (Soini, 2012). With regard to perceptions of CJD as a potentially communicable disease, there might also be more empathy, based on current beliefs about the way that the disease is transmitted, unless a person is held responsible for eating meat or needing a blood transfusion. This is also relevant to the issue of personal responsibility which is addressed in the next section.

Lay people do not all have the same understanding of genetics and may interpret probability of developing a form of dementia differently. Leibowitz (1999) points out that people react very differently to the perceived risk of disease based on statistical probability. Whereas some people will interpret 45% probability as meaning that they are less than likely to be affected, others will treat a 3% probability as very high risk. In its position statement on genetic testing for late-onset Alzheimer’s disease, the American Geriatrics Society

(2000) draws attention to the fact that very little if anything is known about the “genetic literacy” of older adults. Many left school before DNA was discovered and before prenatal genetic testing became available.

The perception of dementia as a contagious condition may lead to fear and the exclusion of people with dementia, as well as stigmatization, which may affect the quality of care that people with dementia receive, as well as their wellbeing. Although, as the means of transmission of CJD, for example, are not related to casual contact (e.g. through touch, saliva or breath), this is unlikely to be the case, beliefs about contagion are not always based on logic or a realistic understanding of the ways in which a medical condition can be transmitted (Bishop, 1991; Rozin et al., 1994).

#### *Restriction of rights and opportunities*

Perceiving people with dementia as children may serve as a justification for some carers to make decisions on their behalf unnecessarily and to deceive them “in their own interests”, thus preventing them from expressing their autonomy (Cayton, 2001). This is patronising as even if a particular person does lack the capacity to make a particular decision, with appropriate support s/he may be able to participate in the decision-making process and in so doing to express his/her autonomy and individuality.

The kinds of activities frequently proposed to people with dementia (which they are then seen to participate in, even if only out of sheer boredom or lack of other more suitable opportunities) may reinforce the images that others have of people with dementia being childlike. In day care centres and care homes where such activities might be proposed, sufficient time and support is not always available to enable people with dementia to use their capacities to their maximum potential (McColgan, 2004). Sometimes it takes longer and involves patience to help somebody to do a task themselves and it is quicker to take over, but this may lead to the kind of excess disability described by Sabat (1994). This dependence on others may then be perceived as child-like and lead to infantilization (Kitwood, 1997) in a kind of vicious circle.

Misunderstandings, or indeed, justifiable predictions, about the role of genetics in the development of AD may contribute towards conclusions about one's own or someone else's prospects for the future (e.g. in terms of health, finances, relationships and wellbeing), perhaps involving a false sense of security or risk. This may result in some limitation of opportunities either available or considered realistic. In the United Kingdom, insurance companies have agreed to a moratorium until 2017 on the use of genetic testing except for life insurance for over GBP 500,000. The Alzheimer's Society has welcomed this moratorium adding that it would be unfair and unjustifiable, based on current genetic knowledge, to discriminate against people with a known genetic predisposition and to collect pre-symptomatic genetic tests results (Southern, 2013). Were this to happen, this might discourage some people from seeking a diagnosis and thus gaining access to care and support, as well as from participating in genetic research, which would deprive them of an opportunity to contribute towards the advancement of science. Current bans on certain people donating blood based on them having received a blood transfusion or having undergone certain medical operations (Public Health England, 2013), whilst a precautionary measure aimed at protecting patients, deprives the former of the opportunity to contribute towards society through an act of solidarity. This may affect their self-image in that they become members of a group which is not only labelled as being “at risk” but also “a risk”.

### *Relationships and individuality*

Considering and treating a person with dementia as a child affects the nature of relationships between people, touching for example on recognised adult status, power relations and the social roles that people occupy as a spouse, lover, parent, friend and grandparent etc. It could be argued that in cases where the person appears to be enjoying a child-like pastime, the focus on the “here and now” is meaningful and may be beneficial. However, it is not necessary to define the person as a child because of this. Comparing the person with dementia to a child detracts attention from their personal history and wealth of experience which is part of their identity even if they cannot remember it.

As dementia progresses and the range of activities that are achievable becomes less, people with dementia may have less choice. Some may enjoy an occasional game of ball, making collages or holding a doll. However, if these were the only activities offered to people with dementia or it was simply presumed that they would enjoy them “because they had become like children”, then it would represent infantilization and a failure to respect their adult status, dignity and individuality. Other meaningful activities should also be possible.



In the following sections, we look at perceptions which focus less on individual characteristics (e.g. related to perceived age, mental health status or biomedical criteria) and more on a global perspective of dementia. The bio-psycho-social and disability models described below both incorporate internal and external factors (e.g. individual personality traits, psychological and emotional factors, biomedical factors and the environment).

### ***A bio-psycho-social phenomenon***

A more holistic perception of dementia has developed over the last few decades based on the rejection of a narrow, biomedical understanding of dementia. Kitwood (1990), for example, was critical of the purely biomedical model of dementia. He emphasised several factors influencing the progression of dementia. For Kitwood, dementia was not simply the result of neurological impairment. He did not deny the medical aspects of dementia but considered that the nature and progression of dementia was not determined solely by the changes in a person's brain but rather by a complex interaction between five factors, namely, health, personality (in the sense of resources for action), biography, neurological impairment and social psychology. With regard to social psychology, Kitwood described a particular way of relating to people with dementia which undermines their personhood, damages their self-esteem and leads to further deterioration of their condition. He called this “malignant social psychology”. Kitwood described this as involving treachery, disempowerment, infantilization, intimidation, labelling, stigmatization, outpacing, invalidation, banishment and objectification, and later added ignoring, imposition, withholding, accusation, disruption, mockery and disparagement (see Kitwood, 1997, pp 46-47).

Kitwood (1997, p.62) also highlighted the possibility of “rementia” (a measurable recovery of powers that had apparently been lost). Examples of rementing challenge the medical model of dementia in that once neurological impairment has occurred and cognitive ability is affected, there should be no improvement other than that brought about by medical treatment. Consequently, dementia is not considered as consisting solely of neurological damage to the brain and the person with dementia is not simply the person who has such damage and must live with the consequences, but rather a unique key actor with his/her

own personality, biography and health status, who through interaction with others, experiences dementia. In this sense, Kitwood described dementia not simply as what a person has but rather what is constructed and experienced by a person through a complex dialectic within a social context.

It is unlikely that members of the general public and even many healthcare professionals would describe their perceptions of dementia in terms of a bio-psycho-social phenomenon. However, such perceptions become apparent when formal and informal carers talk about the importance of understanding and getting to know each person with dementia and when they recognise the importance of the environment and of their own actions towards people with dementia. In such cases, they are not focusing entirely on damage to the brain but recognising that other factors contribute towards effective and ethical care, based on observations of the impact of such factors on the person's wellbeing as well as on the evolution of his/her condition. Moreover, the increasing practice of "person-centred care", which has almost become the standard paradigm for care, and the growing expectations of people with dementia and carers for such care, suggest that dementia is frequently perceived as a bio-psycho-social phenomenon.

Others have put forward variants on bio-psycho-social perceptions, some giving more weight to one element than another. A "bio-psycho-social" model of dementia was proposed by Maisondieu (1989), who developed a psychodynamic model of dementia in which he placed greater emphasis on psychological and social factors contributing towards dementia (rather than biological factors), linked to a pathological fear within society of death. By contrast, Whitehouse (2013) argues in favour of a model which emphasises the broader biological foundation to medicine, incorporating ecological and evolutionary factors.

### ***A disability***

The World Health Organisation (2012) describes dementia as "one of the major causes of disability and dependency among older people worldwide" and states that "The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic" (WHO, 2012). According to the Convention on the Rights of Persons with Disabilities and its Optional Protocol (United Nations General Assembly, 2006), people with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Many people with dementia therefore fall into this category.

Nevertheless, different models of disability have been identified and co-exist. According to the medical model, disability is an abnormal individual limitation resulting from impairment. It is considered a feature of the person; something that was caused by disease, trauma or a health condition (WHO, 2002a). The social model of disability, on the other hand, reflects the view that many of the problems faced by disabled people (including people with dementia) are due to the way that society is organised which is rigid and inflexible, and does not meet their needs. In this sense, disability is not seen as something a person has but something that is done to them (i.e. a person is disabled by society) (Swain, French and Cameron, 2003). Feminist perspectives on disability have helped ensure that the emphasis on the role of society is not seen as supporting the belief that physical differences and restrictions are entirely socially created (Morris, 1991) which would amount to a denial of people's real experience of

their minds and bodies and the significant impact that this may have on their lives. Feminist perspectives on disability have been influential in challenging the pre-eminence assigned to normalcy, strength and independence, and the devaluation of disability and of people with physical and cognitive impairments, as well as fighting for inclusiveness and valuing the experience of disabled people (Silvers, 2009; Wendell, 1996). The bio-psycho-social model of disability, upon which the International Classification of Function, Disability and Health of the World Health Organization, mentioned above, is based, integrates the medical and social factors of disability. It represents a biological, individual and social perspective of disability and functioning, whereby alongside the medical condition and possible impairments, there are contextual factors linked to the environment and the person. Those linked to the environment might include people's attitudes, buildings, systems and legal and social structures whereas personal factors might include age, gender, experience and coping styles etc.

### ***Related ethical issues***

#### *Ethical responsibility for a holistic approach to care*

Bio-psycho-social perceptions of dementia and of disability emphasise the importance of the person without rendering the person individually responsible for his/her condition. Kitwood (1997) described people with dementia not simply as biological entities or the bearers of the condition but as people at risk of losing their personhood and of entering into a downward spiral of neuronal degeneration towards death, based on factors which are not solely biological. Bio-psycho-social perceptions may have an impact on the way that people with dementia are treated, and when translated into action may foster independence, individuality and personhood and thus contribute towards wellbeing, self-esteem and social integration. Perceiving dementia in this way requires carers and society to accept greater responsibility for people with dementia and not seeing the "problem" as residing in the brains of people with dementia. This implies a need for society to respond to and make an effort to accommodate the needs of people with dementia, rather expecting the latter to adapt to existing structures and support which are inappropriate and lead to disability. This also applies in the context of interpersonal interaction in that a bio-psycho-social perception of dementia encourages reflection on the possible impact of one's behaviour on people with dementia. Kitwood's examples of malignant social psychology provide a means for reflection in this respect.

A bio-psycho-social perception of dementia (and of dementia as a disability) calls for a greater human investment in terms of time, effort and expertise. Some nurses and care staff may feel that such an approach sets high standards of care and is sometimes difficult to achieve (Smythe et al., in press). This should not be considered as a negative remark about their willingness or dedication to people with dementia. In some countries, it may simply be difficult to achieve, especially in the domain of residential care where there is often a high turnover of staff who are often, in addition, underpaid, inadequately trained and insufficient in number. This may create an ethical dilemma for such staff who may be constrained by their lack of knowledge and the procedures within some care homes (such as quotas for service provision and set rounds) which limit their opportunities and motivation to take into consideration the non-medical factors which contribute towards the symptoms and experience of dementia.



*Towards a more valued identity*

Recognition that the experience of dementia cannot be reduced solely to changes within the brain, but involves a range of factors which extend beyond the person with dementia, may contribute towards an understanding of dementia as a complex social, medical and cultural phenomenon. This may lessen the tendency to perceive people with dementia as members of a distinct, recognisable group, which is based on a medical diagnosis and positions them as patients or in some way “other”. Kitwood’s (1997) focus on the persistence of personhood and that “the person comes first” is an essential feature of the bio-psycho-social model of dementia which calls for a recognition of the continued and persisting value of people with dementia irrespective of the degree of dementia.

*Possible implications and reaction to classifying dementia as a disability*

The United Nations Convention describes a “paradigm shift” in attitudes and approaches to people with disabilities with a move away from viewing people with disabilities as “objects” of charity, medical treatment and social protection towards viewing them as “subjects” with rights (United Nations, 2012). This perception gives a more prominent place to the individual as a unique person and equal citizen. However, it is not known to what extent this official discourse has become accepted by the general public or whether lay people mainly perceive disability as a stigma.

Shakespeare (2006) points out that many “people with impairments do not want to identify as disabled. They want to get on with their lives, and to participate in the mainstream.” We are not aware of any studies which have explored the reactions of people with dementia to being categorised as disabled. One could ask whether classifying dementia as a disability does not represent a failure to respect the right to autonomy and self-expression of those people who do not wish to be so labelled or do not perceive dementia as a disability. In the UK, with some conditions such as heart disease and cancer, people can apply for a disability card (e.g. for driving) if and when they feel that it is appropriate and would be beneficial to them. Alzheimer Europe (2011) recommended in connection with dementia research that people with dementia should not be labelled in a blanket fashion as vulnerable. As dementia affects people very differently and tends to involve a very gradual loss of capacity in different domains, the same might be applicable in the case of disability.

The support and care of people with dementia is organised differently in different EU-member states. Depending on the country, the authority responsible for care and support may be linked to healthcare, social care, welfare, older people, the family or another domain. Formal recognition that people with dementia have a disability could result in them losing their rights to certain services in certain countries. On the other hand, if dementia is not officially recognised as a disability by the State and by organisations responsible for the provision of support, then it could be argued that people with dementia are being discriminated against.



In this section, we present explanatory models which focus on perceived and in most cases individually-focused causes of dementia, mainly covering,

- possession by spirits or due to spiritual forces and
- personal responsibility

### ***A result of possession by spirits or due to spiritual forces***

The belief that illness is caused not only by intrapersonal or natural factors (such as diet, lack of exercise and smoking) but also by supernatural factors has been recorded in a number of studies involving people from a range of ethnic/cultural backgrounds (Landrine and Klonoff, 1994).

There is archeological evidence in the form of trephined skulls which suggests that as long ago as 3000 BC people may have attributed mental disorders to possession by evil spirits, which needed to be let out of the body (Hinshaw, 2007; Porter, 2003). However, other reasons for trephinations, such as to treat traumatic fractures, are possible and there remains some speculation about the significance of such procedures in different ancient cultures (Hinshaw, 2007; Velasco-Suaraz et al., 1992). In the present day, Martin et al. (2000) found that lay people did not in general attribute mental illness to punishment by God or bad character, and that they were more likely to attribute it to stressful life circumstances, chemical imbalances and genetic factors.

Studies which have focused on dementia suggest that in some cultural and ethnic groups, beliefs about fate, evil spirits, the evil eye, lack of faith in or punishment from God are common (Blay and Peluso, 2010; Downs et al., 2006; Elliot et al., 1996; Hussain, 2001; Mackenzie, 2006; Uwakwe, 2000; Yeo et al., 2007) and in some Chinese communities, dementia is recognised as an illness but nevertheless attributed to spiritual forces (Elliott et al., 1996). The acceptance of biomedical explanations for disease does not necessarily rule out beliefs about supernatural causes. With reference to an awareness campaign for leprosy, Cross (2006) reports that some people accept such explanations but then ask “why him and not me”, inferring that the disease is nevertheless due to mysterious forces.

In a qualitative study involving face-to-face interviews with south Asian carers of people with dementia, it was found that they classed dementia as a mental illness but were sensitive to traditional religious and spiritual explanations concerning the cause of mental illness (Mackenzie, 2006). This included the consequences of an on-going tension between good and evil and the possibility of being possessed by evil spirits. Some described dementia as a punishment for not praying enough, not having sufficient faith to ward off the evil spirits and even as a punishment by God of the carer. Beliefs about spiritual causes of dementia and about biological factors resulting in the development of dementia and its subsequent progression are not necessarily always incompatible. These studies highlight the importance of taking into consideration the perceptions of different cultural groups, including those of ethnic minorities.

### ***A person's own fault***

Some researchers have explored whether people with dementia are considered responsible for having dementia (i.e. to what extent it is perceived as being their own fault). The findings suggest that perceived responsibility is generally quite low (Blay and Peluso, 2010; Cohen et al., 2009; Schomerus, Matschinger and Angermeyer, 2006; Weiner et al., 1988; Werner, 2005; Werner, 2008; Werner & Giveon, 2008). In a large-scale survey carried out by the UK Royal College of Psychiatrists, it was found that only 4% of participants considered people with AD to blame for their condition (Gelder, 2004). In a qualitative UK-based study, none of the GPs interviewed considered that people with AD were responsible for their condition and some suggested that even if this were the case for some other forms of

dementia, nobody should be blamed or treated differently as a result of their possible role in having developed it (Gove, 2012).

Where an element of blame has been detected for having developed dementia, this has been in connection with a range of beliefs about the origin of dementia such as social, physical and emotional factors (La Fontaine et al., 2007), “laziness” and “weakness of character” (Low and Anstey, 2009) and spiritual influences (as mentioned in the previous section). Blame is not always placed with the person with dementia as relatives have sometimes been held responsible based on their failure to provide appropriate care and support (La Fontaine et al., 2007).

### **Related ethical issues**

#### *Cultural sensitivity*

In each society and community, there may be people with very different views about the role of spirituality or religion in relation to the origin of dementia. Not all beliefs about the role of god or spiritual forces are linked to an established religion. Faith is a very personal matter and beliefs may vary between members of the same faith, and between individuals who share a cultural identity. Iliffe and Manthorpe (2004) point out that there is often considerable intra-ethnic group variation. They suggest that ethnicity is too broad a category and that whilst there may be cultural differences and shared meanings, a focus on ethnicity alone may promote misunderstandings. It is therefore important to find out more about people’s individual belief systems and “micro-ethnicity” so as to avoid making assumptions about them or drawing on racial and cultural stereotypes (Healthtalkonline, 2013).

#### *Balancing healthcare responsibilities with respect for individuality and culture*

If explanations for dementia provided by healthcare professionals are so far removed from the understanding that some people have about dementia, they may not be meaningful to those people. Non-medical lay beliefs may interfere with the acceptance of the medical diagnosis, compliance with medical treatment and even presenting to the GP in the first place. Healthcare professionals may be faced with a dilemma similar to that described by Weber (1921) between the ethical principles of ultimate ends and responsibility. It is their moral and professional duty as healthcare professionals to treat patients on the basis of accepted current medical knowledge but this cannot be adhered to blindly (i.e. without due consideration for the person him/herself). Healthcare professionals also have a moral duty to behave responsibly with respect for people’s individuality which includes respecting their values and beliefs, including their spiritual or religious beliefs.

In many countries within Europe, the main dominant religions share a common belief in life after death. Whereas the belief in an afterlife does not interfere with the exercise of medicine and may be comforting to patients, spiritual beliefs about the cause of dementia may be seen to challenge the authority of the biomedical discourse even though the two are not necessarily incompatible. Scodellaro and Pin (2013) point out that lay aetiologies for dementia can be found in every culture and coexist alongside medical explanations. They suggest that such explanations may help people to make sense of disease rather than challenge medical aetiologies. On the other hand, some beliefs of lay people be accompanied by beliefs about relevant interventions, such as praying, fasting, beatings and night vigils, which may be preferred.

Attempts to challenge the beliefs of individuals or communities about issues relating to spirituality and religion could be interpreted as attempting to impose the dominant cultural view on those individuals and groups, thereby failing to respect their freedom of thought. On the other hand, failing to pursue a medical diagnosis and treatment for identifiable cultural groups could lead to inequity in the provision of care and could be interpreted as racial discrimination.

#### *The possible impact of blame*

According to Weiner et al. (1988), certain attributions about the controllability of a condition may affect how people react to people with that condition. Three attributions have been identified: 1. whether the condition or situation is controllable, 2. whether the person could be considered responsible for having it or for its occurrence and 3. whether s/he could have prevented it (Weiner et al., 1988). Lack of perceived responsibility may work in a person's favour (e.g. eliciting understanding, empathy and assistance) whereas perceived responsibility may work against them, provoking anger and punishment (e.g. resulting in a negative response such as social distancing or coercion).

In other domains, such as anorexia nervosa and lung cancer, beliefs about people's responsibility for the condition have been associated with lower levels of tolerance or sympathy for them, as well as some degree of healthcare discrimination and stigmatizing attitudes (Brotman, Stern and Herzog, 1984; Crisafulli, Von Holle and Bulik, 2008; Chapple, Ziebland and McPherson, 2004). This might reflect what Ryan (1971) described as "blaming the victim". Despite low levels of perceived responsibility for dementia, concerns are frequently expressed about the poor quality of care given to people with dementia in terms of available services and support, and the treatment of people with dementia in residential care. This suggests that people with dementia are perceived as being discriminated against but that the general public does not find such treatment acceptable. As researchers discover and communicate various lifestyle factors (e.g. linked to exercise, obesity, mental stimulation and alcohol consumption), which increase the likelihood of developing dementia, issues related to perceived responsibility and blame for dementia may gradually change. On the other hand, perceived responsibility may still be given little attention as other issues related to the social saliency of dementia and the anxiety that dementia arouses in many people may be more significant in shaping attitudes towards and the treatment of people with dementia.

## **Words**

This section is about the words we use when writing or talking about dementia and people with dementia. Language has been described as "a powerful and ever-evolving force for social change" (Whitehouse, 2013, p.107), with keywords sometimes capturing our imagination, conjuring up vivid images (especially through the use of metaphor) and even serving to achieve strategic goals (see section on "strategic communication"). On the other hand, people sometimes use words out of habit, without reflecting on the meanings and language use is also dependent on numerous factors such as who is speaking and to whom, the context, the mood or atmosphere, the person's feelings about dementia, whether the person is comfortable with the topic, as well as factors linked to specific cultures (e.g. history, traditions, literature, beliefs and linguistic norms). Words represent concepts and reveal something about the taken-for-granted reality of our social worlds. In this section, we will examine:

- developments in terminology,
- medical terms,
- informal or descriptive terms,
- euphemisms and terms with derogatory undertones.

### ***Developments in terminology***

As mentioned earlier, a clear differentiation between different types of mental disorder and what is now recognised as dementia did not exist for many years. Terms which were used in the past, which seem to describe what we now call dementia, include senior idiocy, foolishness associated with age, dotage and morosis (Berchtold and Cotman, 1998). These terms highlight the loss of reason more than the loss of cognitive functions such as memory, which creates an association with mental disorder (sometimes referred to by lay people as madness or insanity). In the literary world, Shakespeare nevertheless made a clear distinction between “senile decay” and “plain madness” and described the characteristics of each (Mahendra, 1987).

In 1907, Alois Alzheimer reported the case of a middle-aged woman with a specific disease which he considered to be distinct from “senile dementia” but this specificity was later questioned (Derouesné, 2008). Nevertheless, during the 1960s, the terms “dementia of the Alzheimer’s type” (DAT) and senile dementia of the Alzheimer’s type (SDAT) started to be used. The term “Alzheimer’s disease” tended to be used to refer to certain cases which would otherwise have fallen into the category of “pre-senile dementia”, but was later also applied equally to cases of “senile dementia”. In this way, the term lost its association with senility as the reference to age was dropped (Swane, 1996). The implication of this was that cognitive decline was no longer officially construed as a condition of old age. On the other hand, debates continue about whether AD in younger people should not actually be considered as a separate disease to that in older people as was initially the case.

It is important to realise that whilst AD is generally considered to be the most common form of dementia, there are over a hundred different diseases which can lead to dementia. Some are named after the scientists who first identified them, whereas others are named on the basis of prominent characteristics or underlying causes. As AD is the most common form of dementia, these other forms tend to receive less attention. The focus on AD and memory problems may lead to the specific features of other forms of dementia being overlooked. For an overview of different types of dementia, please see: <http://www.alzheimer-europe.org/Dementia/Other-forms-of-dementia>.

### ***Medical terms***

In some cultures, people are more comfortable with the term “dementia” and avoid saying “Alzheimer’s disease” whereas in others, the exact opposite is the case. Such differences may occur in populations using the same language and even amongst people from different regions.

In the context of a qualitative UK-based study into GPs’ perceptions of dementia, most preferred the term “dementia” (Gove, 2012), whereas in two qualitative studies involving Australian GPs, avoidance of the term “dementia” and a preference for euphemisms, such as “memory problems”, were reported (Phillips et al., 2012; Robinson et al., 2008). In all three studies, GPs were influenced in their choice of words by their perception of what the terms signified for lay people.

This was echoed by Girard and Ross (2005) who, commenting on the use of the terms “dementia” and “demented”, suggested that both were accepted terms in the healthcare profession with no pejorative connotations, but added that the same could not be said regarding the use of these two terms by the general population for whom they were synonymous with “madness” and being “crazy” or “insane”. In the Czech Republic, healthcare experts often specifically refer to the “syndrome” of dementia (Holmerova et al., 2009 and 2010), which perhaps serves to emphasise that it is a reference to a varied medical condition. In the UK, some healthcare professionals have reported being asked not to mention “the D word” (Milne, 2010), whereas in the US, it is “the A word” that is considered problematic (Kissel and Carpenter, 2007).

*“I get asked all the time, “Please don’t mention the A word”. That’s what it’s called; it’s called the A word. And I will be sensitive to that.” (Kissel and Carpenter, 2007, p.277)*

Different lay people may have different preferences for terms, such as dementia, Alzheimer’s disease or terms denoting other forms of dementia. However, there is also some evidence that many lay people do not understand the difference between dementia and Alzheimer’s disease and sometimes the terms are used interchangeably (Devlin et al., 2007). In addition, lay people may not even associate symptoms of AD with either term. In a study by Werner and Davidson (2004), lay people were given a vignette of a person with AD and asked to state what condition the person had. Although three quarters recognised a health problem, only one third correctly identified the person as having AD. An additional 6% described the person as being confused, 13% as having a memory problem and 14% as having orientation problems. The different terms used by lay people for dementia and AD may be based on classifications which do not reflect those used by healthcare professionals and researchers. Some healthcare professionals and service providers are also unsure about the difference between the two terms. To complicate matters, there are now differences in the official terminology used in the Diagnostic and Statistical Manual of Mental Disorders V (described earlier) and the International Classification of Diseases published by the World Health Organisation.

In some languages, words derived from medical terms are used to label people with dementia or AD. In France, for example, a person might be referred to as a “*dément*”, an “*Alzheimer*” or an “*Alzheimérien*” (Ngatcha-Ribert 2004). In the Netherlands, there is a noun ‘*dementerende*’ (a person who has dementia), which is no longer very common but is still used by some care professionals.

### ***Informal or descriptive terms***

In 1998, Braun and Browne explored perceptions of dementia of Asian and Pacific Islander Americans, covering 5 major subgroups: Chinese, Japanese, Filipino, Vietnamese and Hawaiian. They provided information about various terms used for dementia and for people with dementia. Chinese immigrants in Honolulu, for example, reported a few Cantonese phrases such as *lo ivan chi oi zeng* (confusion in old age), *fan low wang tong* (old return to youth) and *sun fa* (confused and of a different spirit). Amongst the Japanese immigrants, the term *bokeru* was used which was translated as “to go senile” or “to become forgetful in old age”. Participants originating from the Filipinos reported terms such as *nagbabalik sa pagkabata* (going back to childhood), *tumatandang paurong* (growing old backwards), *utianin* (occasional forgetfulness), *wala na* (gone, there is none) and *tapos na* (done or finished). The Japanese immigrants mentioned another term (*kichigai*) which means crazy

or insane but this was mostly associated with psychiatric problems. Similarly, the term *kabaw* (from Ilokano, the language from the northwestern provinces of the Philippines) was also used broadly to refer to people who are considered “forgetful, retarded or otherwise impaired mentally”. With regard to the terms used to refer to cases of probable dementia, the different terms mainly reflect a perception of dementia as a combination of being old, forgetful and confused, but also of reverting to childhood and in some cases of a loss of one’s spirit. As mentioned earlier, the belief that dementia was a natural part of the ageing process was stated. It is not clear from the report to what extent the above-mentioned terms were used solely by lay people or also by medical professionals. A series of focus groups and interviews about the perceptions of African American, Chinese and Latino carers in the United States also revealed that signs of early memory loss were considered as normal ageing and described in terms which reflected a disease of old age, memory loss linked to old age and bad “feng shui”, and madness, respectively (Mahoney et al., 2005).

### ***Euphemisms and terms with derogatory undertones***

Terms which are frequently used to refer to people with dementia are sometimes also applicable to people with a wide range of mental disorders or psychiatric symptoms. Examples of such terms, reported mainly in qualitative studies, include “turning dotty”, “losing your marbles”, gone “doolally”, being “batty”, not being “right in the head”, gone “gaga” and “losing it” (Corner and Bond, 2004, Gove, 2012; Milne, 2010).

*“Oh, I’m turning into a typical dotty old lady; I can’t remember a thing. My memory is so bad these days.”*

*“I go upstairs and forget what I’ve come for (...../.....) I think Oh God! I’m losing my marbles.”*

*(Corner and Bond, 2004, p. 147).*

In a small-scale qualitative study, which involved asking twelve men and women in the early stages of dementia what they thought other people understood by the terms dementia and Alzheimer’s disease, terms with similar connotations were mentioned such as “demented”, “short on top”, “a screw loose”, “a bit funny”, “crackers” and “need to be locked up” (Langdon et al., 2007). Some of these terms are similar to those used by American schoolchildren to describe mental illness in a study by Rose et al. (2007).

Euphemisms are used by healthcare professionals as well as by lay people (Downs et al., 2002; Gove, 2012; Phillips et al., 2012). For example, 94% of a sample of 114 GPs attending a training session on dementia in Scotland revealed that they only used euphemistic terms (such as memory problems and confusion) when telling a person with dementia about the illness (Downs et al., 2002).

Some terms are used euphemistically, others in a derogatory manner and sometimes, the difference between the two can only be detected in the manner and context in which the terms are used. The term “demented” is unusual as it continues to be used in some medical circles and by some researchers in a neutral manner (i.e. without any desire to be offensive) even though it is increasingly considered as being offensive. This may be due to its original meaning (i.e. “out of one’s mind”) but also as the term “demented” can be used in English in a derogatory manner to refer to a person who is considered insane based on the now obsolete verb “dement” (to drive mad) (Douglas Harper, 2012); and because it turns a description into a label for the whole person, thus completely dominating their identity.

### ***Related ethical issues***

Terms used to refer to dementia and people with dementia convey information about the perceived origin, nature and experience of dementia. This may affect the way that people with dementia perceive themselves and are treated within society, thus having an impact on quality of life, self-esteem and social inclusion. Depending on the situation and the people involved, this may result in discrimination such as people with dementia being denied access to certain nursing homes or to operations. Many of these issues have been associated with stigma through the concept of labelling. Labelling is part of the process of stigmatization but it does not necessarily cause stigma. Lots of groups in society are labelled (e.g. cyclists, volunteer fire-fighters and brunettes) but not stigmatized. When the label is socially salient and associated with a series of other factors (e.g. stereotyping, cognitive separation, loss of status, etc.), stigmatization may occur. For further details, please see the definition of concepts in the introduction).

#### *Concerns about labelling*

Whilst labelling can have a negative impact, labels can sometimes have a positive impact, implying, for example, that a person is not to blame for their condition and resulting in positive feelings towards the person (Weiner et al., 1993). In an American study involving psychology students, greater sympathy, less anger, less judgement of responsibility and greater willingness to help was associated with the label Alzheimer's disease than that of major depression (Wadley and Haley, 2001). Although healthcare professionals may have concerns about labelling people as having dementia (i.e. disclosing a diagnosis of dementia), the consequences are not always negative. The diagnosis may also help the person to understand changes they are experiencing, plan for the future and obtain support and treatment. It is a biomedical ethical, and in most cases a legal, obligation to pursue a proper diagnosis of dementia and to give people the opportunity to be informed of the diagnosis.

#### *Diagnosis and participation in research*

The desire to avoid being labelled as a person with dementia may delay diagnosis and lead to people not accessing timely treatment and support, which may also have a negative impact on carers. Ben-Zeev, Young and Corrigan (2010, p. 320) describe such label avoidance and associated denial of group status as "perhaps one of the most significant ways in which stigma impedes care seeking." Failure to seek a diagnosis in the light of dementia-related symptoms also contributes to the number of undiagnosed cases of dementia which affects the number of people who could take part in dementia research. Garand et al. (2009) point out that research which draws on participants from an Alzheimer's disease Research Centre is not likely to be representative as the sampling would exclude people who are fearful of a diagnosis of MCI or dementia. The fear is not necessarily of acquiring the label but of everything that the label sums up in people's mind. In the context of research, this means many people with dementia will not contribute towards society and towards future developments in dementia care and treatment.

#### *Dignity and respect*

It seems unethical, in terms of respecting a person's human dignity, to offend the very group of people for whom treatment, care and research are intended, knowingly, through the use of the term "demented". It is a linguistic choice. Alzheimer Europe explicitly asks speakers to avoid the use of certain terms and suggests alternatives. The aim is not to police language but to inform speakers about the possible impact of certain terms on



those concerned. People are then free to use the terms they choose and some do use the term “demented”. This is mainly an issue linked to the English language but the problem extends beyond Anglophone countries as English is frequently the official language used at large conferences and in numerous English-language, peer-reviewed scientific journals.

The English language is a living, dynamic language. New terms are constantly being defined and added to dictionaries, some are labelled “archaic” and some are labelled “offensive”. The following example is taken from the online Dorland’s Medical Dictionary for Health Consumers (2007):

mongolism/mon-go-lizm/ (mong´go-lizm) former (now offensive) name for Down syndrome

However, this is not yet common for the term “demented”. This term is often followed by definitions such as “mentally ill/insane”, “suffering from dementia” or “pertaining to a form of mental disorder in which cognitive functions are affected” (The Free Dictionary, Farlex inc., 2013). As perceptions of dementia change along with their associated meanings, certain terms such as “demented” may also eventually become obsolete.

The French and Dutch terms mentioned earlier (*dément*, *Alzheimerien* and *dementerende*) are different from the English term “demented” as they are not used as adjectives describing attributes that a person has but as nouns describing what a person “is”. This is similar to the practice of calling people with schizophrenia “schizophrenics” in that it reduces a person to a disease state. Ngatcha-Ribert (2004) suggests that a person who is thus designated is then treated like an object which is moved about and manipulated.

The appropriate use of medical terms, on the other hand, is sometimes considered as providing legitimization and greater respect for people with dementia. It may result in them being considered as having a recognised medical condition for which they are entitled to treatment, care and support, as opposed to what was previously rather vaguely considered as senility and kept hidden within the family, as the following quote demonstrates.

*“We no longer hide granny who has gone gaga, but we have our grandmother who has Alzheimer’s disease, and there we find credibility in a new discipline and in a disease for which there are researchers who say but of course, Madame, it’s not because you’re losing your mind, you have neurofibrillary neurodegeneration....” (Geriatrician cited in Ngatcha-Ribert, 2004, p.54 – our translation).*

## Metaphors

### ***About the use of metaphor***

Metaphors are used in all aspects of communication (e.g. in conversations, books, newspaper articles, artwork, political speeches and films). Zeilig (2013, p. 2) defines metaphors as “set[s] of linguistic processes whereby aspects of one object are carried over or transferred to another object”. She further explains that the metaphor involves an implicit comparison between two dissimilar things (often difficult concepts), with the unfamiliar/difficult thing being described by the familiar thing without the need to state “as” or “like”. This renders concepts and experiences which are hard to grasp or address more tangible. It also has implications for the way we think and perceive the world as the meaning of the metaphor is carried over to that to which it is linked (Zeilig, 2013).

Lakoff (1991) suggests that “metaphorical thought, in itself, is neither good nor bad; it is simply commonplace and inescapable. Abstractions and enormously complex situations are routinely understood via metaphor. Indeed, there is an extensive, and mostly unconscious, system of metaphor that we use automatically and unreflectively to understand complexities and abstractions.” Unfortunately, it is not always possible to determine whether its use is simply a reflection of the society in which a person lives and has constructed meaning, or a deliberate and selective attempt to draw on certain meanings and associations with which the person is familiar, and presumably other people too, for various reasons. Sometimes metaphors are used so often that they lose their significance with the result that the use of clear terms would be much more powerful. Reflecting on her earlier work “Illness as Metaphor” (and on what she meant by “metaphor”), in which she criticised the use of fighting terminology, Sontag (1990) suggested that metaphors can be unhelpful or harmful.

*“Of course one cannot think without metaphors. But that doesn’t mean there aren’t some metaphors we might well abstain from or try to retire from”. (Sontag, 1990, p.93)*

### ***Dementia or Alzheimer’s disease as metaphors***

Gzil (2014) describes AD as an emblematic illness; the mythical illness of the contemporary world. Far from suggesting that AD is not a disease but a social construction or a myth constructed by pharmaceutical companies, doctors and associations, he suggests that AD has acquired a symbolic power and has become “a figure, an emblem, a metaphor, a myth in the anthropological sense of the term” (Gzil, 2014, p.9). This perspective is in keeping with Susan Sontag’s famous work “Illness as a metaphor” (1978) in which she suggested that people project their feelings about evil on to certain diseases (such as the plague, leprosy, syphilis, cholera, tuberculosis and more recently cancer and AIDS) and that those diseases (which are then enriched with those meanings) are then projected onto the world. Descriptions of dementia as evil and wicked are not uncommon (Connolly, 2013). The disease itself becomes a metaphor and everything that the disease sums up in people’s minds is linked to other things. Zeilig (2013, p.5) proposes what she describes as a simplistic equation for dementia as a metaphor, namely: “Dementia = a complex, unknowable world of doom, ageing, and a fate worse than death”. Gzil (2014) links the mythical status of AD and the threat that AD symbolises to the metaphor of the zombie (see subsequent section) and to existential anxieties whereby the fear is not of a violent death but of a long, drawn-out life, a life which is no longer considered a life, or at least not a life worth living.

In drawing attention to the use of certain metaphors for cancer, as well as tuberculosis and later AIDS, Sontag’s publication led to greater awareness of metaphors and reflection on the possible impact of their use. Speaking from her own experience of having cancer, Sontag (1990) urged people “to regard cancer as if it were just a disease – a very serious one but just a disease” (Sontag, 1990, p.103). In the following sub-sections, we highlight some of the metaphors surrounding dementia and at the end consider the possible implications of using metaphors to portray dementia and people with dementia in this way.

### ***The brain and the head***

Numerous metaphors for dementia are used which focus on the brain or the head. Examples of metaphors used in the United Kingdom, Belgium and the Czech Republic include

the brain being “scrambled”, “transformed into Gruyère cheese “not working well”, the head being full of “snow” or “fog” and “having a short circuit” or “wind” in the head (Gove, 2012; Janakova, 2013; Van Gorp and Verduyse, 2011).

### ***Flooding/uncontrollable natural disasters***

Zeilig (2013) describes how dementia has long been associated with the danger of flooding (e.g. the rising tide of dementia, the silent tsunami, the wave of dementia). This could be interpreted as the threat of a natural disaster, something uncontrollable or unstoppable and even in biblical terms as a threat to the survival of humanity. Diseases, such as ovarian cancer, which often do not have noticeable symptoms until they are fairly advanced are frequently referred to as silent killers (Cornforth, 2009). Whilst this is not the case with dementia, for which there are often noticeable signs, the flooding imagery may symbolise “an unstoppable force of nature coupled with quiet stealth” (Zeilig, 2013, p. 3). When natural catastrophes occur, their indiscriminate nature is often emphasised. Everyone is at risk.

### ***Dementia as an epidemic***

AD has been described as a “silent epidemic” (Gubrium, 1986, p.34). The metaphor of an epidemic implies something that spreads rapidly and extensively through infection but the term can also be used figuratively as simply meaning something that is widely prevalent. According to Ngatcha-Ribert (2004), this perception is often fuelled by media reports which suggest a soaring epidemic looming up on horizon which will affect everyone directly or indirectly. This may be reinforced by astronomical figures linked to the estimated cost of future care (Sontag, 1978).

### ***Wars, fighting and crusades***

Military metaphors became increasingly common in the field of medicine in the 1880s following the identification of bacteria as agents of disease (Sontag, 1978) and again after the Second World War, when military metaphors were promoted in cancer care (Lane et al., 2013). This has typically involved the portrayal of “combatting” diseases such as cancer, and the use of fighting terms such as wars, battles and crusades. The metaphor of war also applies to dementia and has been used by the general public, people with dementia, doctors, researchers, Alzheimer associations, the press and politicians alike as the following examples demonstrate.

*The UK Prime Minister David Cameron stated, “We’ve got to treat this like the national crisis it is. We need an all-out fightback against this disease, one that cuts across society.” (Weston, 2012) and the slogan on the website of the Department of Health dedicated to addressing dementia is “the dementia challenge: fighting back against dementia” (<http://dementiachallenge.dh.gov.uk/> - accessed in July 2013).*

*A press release from the US Department of Health and Human Services presenting the US national dementia plan stated, “Obama administration presents national plan to fight Alzheimer’s disease” (<http://www.hhs.gov/news/press/2012pres/05/20120515a.html> - accessed in July 2013).*

*The current slogan of a UK-based Alzheimer’s Society is “leading the fight against dementia” (<https://www.alzheimers.org.uk/> - accessed in July 2013).*

*“Well then you decide, well OK, we’ll fight it as long as we can.” (Iain, cited in Clare, 2002).*

The above citations provide examples of the way that dementia is personified as an attacker and people with dementia, the government and Alzheimer Associations as being ready to fight or fight back against the attacker. The frame of the invader, identified by van Gorp and Verduyn (2011), might also suggest “taking over” and exercising power over those who have been invaded. Whilst wars bring suffering and fear, they may also be perceived as energising and uniting people against a common enemy. The calls from governments for action and from Alzheimer associations to lead the fight suggest that people with dementia are not fighting alone. This suggests solidarity and the perception of people with dementia as “one of us”.

The language of warfare may encourage people to view people with dementia “as “victims” who are ravaged by a singular marauding disease” and it personifies AD “as a “mind-robber” that “attacks” or “strikes” the brains of individuals leaving plaques and tangles in its wake” (George, 2010, p. 586). Statements about fighting could be interpreted in a positive sense as taking action whereas fighting back might be interpreted as being slightly more defensive which, when considered in connection with other metaphors which depict dementia as catastrophic and uncontrollable, might be perceived as a weak position to be in.

The term “victim” has been used not only in relation to people having dementia and in relation to war terminology but also to the poor quality treatment and even abuse sometimes experienced by people with dementia within the healthcare system. At the same time, Ngatcha-Ribert (2004) highlights the way that informal carers are often portrayed as the “real” victims of dementia, the implication perhaps being that people with dementia are also victimizers (unless it is dementia as a personification which is perceived as the victimizer).

### ***Zombies and monsters***

The metaphor of the zombie is slightly different to other metaphors in that it is not linked to a single characteristic and may be used without necessarily making explicit reference to zombies (Behuniak, 2011). Rather it is based on the portrayal of people with dementia as sharing certain characteristics with zombies (as portrayed in literature and films). Behuniak carried out an analysis of references to such characteristics in relation to people with dementia in English-language medical journals and based on the portrayal of zombies as dispossessed entities in three films by Romero (dated 1968, 1978 and 1985). The three zombie-like characteristics, described by Behuniak as having been used to depict people with AD, are appearance, loss of self and loss of the ability to recognise others. Three additional characteristics are linked to the disease itself, namely the epidemic threat, widespread cultural terror and death as being preferable to becoming an animated corpse. The metaphor of the zombie has been described as reflecting the perception “at the collective level of a scourge which infiltrates and invades society” (Gzil, 2014, p. 9).

The metaphor of the zombie (a dead body which has been given the semblance of life due to possession by a supernatural power) (Behuniak, 2011) is also relevant to understandings of a mind-body split. According to Aquilina and Hughes (2006), zombies are “treated as already dead and as walking corpses to be both pitied and feared, despite their obvious signs of life” (p.143), which creates a further link to the concept of a “social death”. These two issues are discussed in the section on “The person with dementia”.

### ***Emptiness/absence of the “real person”***

Metaphors are often used which reflect a perception of people with dementia being physically present but mentally absent or disconnected from the world around them. Terms and images reported include “off/away with the fairies”, “lights on, no-one home”, an “empty shell”, “not being there”, “sitting there like vegetables”, the person just being “a body”, “vegetables in a parallel world” and a “speechless shadow” (Devlin et al., 2007; Dunham and Cannon, 2008; Gove, 2012, Piehl, 2009, Swane, 1996). This reflects dualism as the implication is that the person’s body is there but their mind is not (see sub-section on dualism). It is as though the physical body is just a container of the mind. The “real person” is believed to be found in the mind.

In 2004, Christine Bryden, who has dementia, spoke out at a dementia conference about the unacceptability of using terms such as “mindless empty shell” in connection with people with dementia. Many references to this term now reflect attempts to demonstrate its inappropriateness to describe the experience or state of people with dementia (i.e. calls not to refer to or consider people with dementia in this way). Nevertheless, some carers still use the metaphor in accounts which illustrate their understanding of dementia. An example is the poem “Cecilia’s Long Goodbye” which includes the phrases “to be reduced to a mere shell like this is more than just a shame” and “for though your body is here, it is just an empty shell” (Podlesak, 2013). In contrast Anderson (2012) develops the shell metaphor further and emphasizes that it is not empty. He states:

*“During my work with families I have heard many people use the phrase, “empty shell of a person” when describing a loved one ravaged by the later stages of the dementia. .../... those living with dementia are far from “empty shells.” Yes, the shell may become more and more difficult to open. Some days it might not open at all. But never forget that there is a beautiful, unvarnished pearl within. Understanding how to “open the shell” gives us opportunities to meaningfully connect with our dementia-afflicted loved one—even if only for a fleeting moment. Just as the right tools and a lot of technique is required to shuck an oyster, there is technique and artistry involved with communicating or connecting emotionally with a loved one who has dementia.”*

### ***The ghostly/disappearing person***

People with dementia are sometimes portrayed as fading away or becoming progressively invisible. This was the theme of a television advert to raise awareness of dementia which was funded by the National Health Service in England (see: [https://www.youtube.com/watch?v=TLpVqc0w\\_Ao](https://www.youtube.com/watch?v=TLpVqc0w_Ao)). The message of the advert, according to Burstow (2011), was that whilst it was difficult for the daughter in the advert to discuss the issue with her father, acting on her concerns and getting help meant she could “keep the dad she knows for longer”. The producers may have been drawing on their understanding of common perceptions of dementia in an attempt to convey a positive message about the benefits of timely diagnosis. However, the image of the fading person who progressively “returns” is reminiscent of ghosts, which may create a symbolic link to death. The image sums up a distant, unreachable presence which is a contrast to metaphors of a bodily presence and absent mind.

## ***Dementia as a journey***

The metaphor of the journey has been used to describe the experience of living with dementia as opposed to fighting it. Three people with dementia from Scotland produced a booklet targeted at people who had been newly diagnosed with dementia. Its title was "Don't make the journey alone: a message from fellow travellers". At the end of the brochure the authors state,

*"We are travelling from an old life to a new. If you can think in a positive way and get the help and support you need, the journey can be brighter and less frightening. Remember you do not travel alone." (Pat, James and Ian, undated)*

Writing in the context of cancer, Ruff (2013) suggests,

*"On a journey, we can appreciate the beauty we encounter and have deep conversations with those who travel alongside us (instead of the chaos and conflict that characterize a battlefield, strewn as it so often is, with the destruction and detritus of war)."*

## **Related ethical issues**

### *Helpful or harmful?*

Metaphors can be helpful. They may enable people to understand a complex medical condition for which there is no cure, for which the causes are multiple and not clearly defined and for which the individual prognosis is not known. Louis Pasteur used invasion imagery to explain his new discovery to the public in 1864 but according to Wiggins (2012), the subconscious impact that allegories such as this have on people is not fully understood and with regard to military metaphors, it is time for a new imagery, which does not place people under pressure to be positive and proactive.

In the context of warfare metaphors, dementia can be perceived as something that can be fought against, thus giving people a feeling that they are actively doing something. Fighting back may also symbolise the refusal of victim status. Nevertheless, in case of defeat or the loss of a "personal battle", there is little room in the warfare metaphor for a positive feeling and self-image as the world around continues to battle on. People may be left with the feeling that they did not battle hard enough, long enough or wisely enough and the idea that some battles cannot be won despite everyone's best effort is rarely put forward (Ruff, 2013). Terry Pratchett, a well-known British writer with dementia, stated, "You can't battle it, you can't be a plucky 'survivor'" (Alzheimer's Society, 2008, p.x).

The warlike terminology personifies dementia as the enemy with whom we must fight. But how do we actually win? If dementia really were a person, in a war situation this would imply killing him or her or at least ensuring that s/he is no longer a threat. In disease terms, this might involve preventing or curing the disease. George (2010) suggests that the warfare metaphor is not helpful in that prevention, halting, reversing, fighting, arresting and curing are not currently realistic, attainable goals for the near future. He proposes shifting the focus from cure to the concept of postponement. He adds that as everyone undergoes neuropathological changes, this focus would foster empathy and nurture the capacity to feel interdependence and solidarity for those who are more profoundly affected by such changes. One could also ask if it would not be better to avoid the use of metaphors altogether, at least in official or public messages about dementia, and to focus more on edu-

cating people in a way that is scientifically accurate and at a level which the general public of today is likely to understand.

The use of metaphor may affect the way that people relate to others who have dementia and may result in negative stereotyping, i.e. additional characteristics being attributed to people with dementia. This may lead to an inaccurate understanding of dementia and negative attitudes towards people with dementia. Stereotypes and images based on metaphors may be fairly powerful and prevent people from recognising the individuality of each person with dementia. Care ethics emphasises the importance of relationships and the person's history and uniqueness as a person. Perceiving people with dementia as objects or in some way absent is therefore likely to have a negative impact on the provision of care. The misunderstandings and attitudes resulting from perceiving people with dementia in that way may affect the way that people with dementia are valued, the relationships people have with them and the care and support they are given.

#### *Coping with perceived threat*

Through the use of metaphor, the disease can be given an identity (e.g. of a flood, a monster, an attacker etc.) which can be visualised and emotions projected onto it. It can be blamed, hated and avoided. Natural disasters might, on the surface, merely symbolise something that is threatening (like dementia) and which necessitates concerted action on a large scale to protect citizens from it. However, such disasters may be less threatening than dementia (for those who have no personal experience of them) due to the fact that they are exterior and relatively rare. The fear of something that cannot be seen or fully understood can be transposed onto something exterior which is more familiar, less threatening and can be seen and practically avoided.

#### *Personhood and social exclusion*

The inhuman, monster-like portrayal of people with dementia, as well as the ghostly disappearing self, seem to challenge the notion of individuality, human dignity and personhood in that the changed behaviour and appearance of the person are emphasised at the expense of their personality, character, individuality and identity. Some people may find such metaphors helpful as a means to avoid blaming the person with dementia. Perceiving them as something different may serve to lessen their perceived responsibility for behaving in a certain way and enable carers to retain a positive image of them. However, it is unlikely that this would be helpful to people with dementia in terms of their being treated with consideration and respect.

Portraying people with dementia as monsters or zombies positions them as an out-group (i.e. they are monsters and zombies, we are not), may contribute towards their stigmatization and, in keeping with the function of metaphors, create an association to characteristics of the specific metaphor which in this case might be fear, horror, loathing and disgust. Such metaphors might also be interpreted as symbolising a radical and irremediable change or loss of the person they used to be. Green (2009) describes the threat of the "other" in relation to long-term conditions:

*"However, people who carry a stigma are the embodiment of the ambivalent, dangerous "other". People with a long-term condition may be treated as such, seen as polluting and contaminating, and dealt with by using exclusionary tactics to locate them both physically and symbolically as far away as possible from the self." (Green, 2009, p.21)*

This fits in with the theory of the belief in a just world in which perceived similarity with members of the out-group can be threatening (Lerner, 1980). This is one example where a counter-frame, in this case an alternative metaphor, might be helpful. Van Gorp et al. (2012) proposed the metaphor of “the strange companion”, a more positive personification which symbolises a second person rather than the tragic transformation of the person him/herself into something to be pitied or feared.

## Strategic communication

In everyday life, the way that dementia is perceived and portrayed is influenced by a range of factors including interaction with other people, personal experience and the media<sup>2</sup>. Often, people are unaware of why they perceive and portray dementia as they do. However, particular ways of perceiving and portraying dementia can also be communicated in a strategic way. In other words, organisations and individuals may sometimes have reasons to transmit or convey a certain perception or understanding of dementia (e.g. linked to its causes, how it is experienced or its impact on individuals and wider society). This may, in turn, be linked to beliefs about how to address dementia as a public health issue, the place of people with dementia in society or methods to tackle dementia-related stigma.

The strategic communication of dementia may be overt or covert. Sometimes there may be a hidden agenda but sometimes the reasons for the choice of terms, analogies and images may be openly stated, either in the communication itself or elsewhere. In some contexts, the way that information about dementia is communicated reflects the official discourse of governments or other official/professional bodies but does not necessarily reflect the perceptions of the individuals employed in those organisations.

At the interpersonal level, people may try to portray dementia in a certain way in order to achieve a particular goal. In the past, much communication about dementia was made by healthcare professionals and informal carers. People with dementia are now increasingly challenging current perceptions of dementia, by speaking publicly at dementia conferences and through publications, reaching a wide audience including the general public, healthcare professionals, researchers and policy makers. Such communication can perhaps be considered as strategic in the sense that people with dementia are openly challenging some of the ways in which they are currently perceived and portrayed.

The phrase which originated from the disability movement “nothing about us without us” is often cited and the necessity to involve people with dementia more actively in the dementia movement as well as in the development of national and European policy is increasingly being recognised. This involves more than representing or being open to the views of people with dementia but also ensuring that their views are heard, and that they are provided with opportunities and, when necessary, support to make their voices heard and to speak about issues that are important to them. In 2012, building on the experience of Alzheimer Scotland at national level, Alzheimer Europe established a European working group of people with dementia to inform its own policies, with the chair of the group having a place on the board. The involvement of people with dementia in conferences, working groups and the Alzheimer Europe board is in keeping with Alzheimer Europe’s 2011 to 2015 Strategic Plan to make dementia a European priority.

<sup>2</sup> See also “the use of frames in the media” in the section on “The portrayal of dementia in the media”.



In addition to transmitting key messages, strategic communication is also about the specific choice of words. Many healthcare professionals are aware of the impact of language but they do not all agree on how it can contribute towards minimising harm and/or bringing about positive change. As mentioned earlier, some avoid the use of certain terms and use euphemisms (Phillips et al., 2012). Others deliberately use terms such as dementia and Alzheimer's disease, albeit in a sensitive manner, as a means to overcome perceived stigma, sometimes basing this approach on perceived changes in attitudes towards cancer over the last 20 years (Gove, 2012).

At a wider level, Ballenger (2006) provides an in-depth analysis of the way in which Alzheimer's disease came to be accepted in America as "a viable project for modern biomedical research" (p.101) and as a major public health issue. He describes how some scientists openly stated their objective "to persuade people that Alzheimer's disease is a disease and not simply what used to be called "senility" or "senile dementia". He also describes how Butler highlighted the perceived importance of naming a particular disease, which is meaningful to people, rather than focusing on the need for basic science as a means to obtain funding for research into Alzheimer's disease. Butler called this approach "the health politics of anguish" (cited in Ballenger, 2006, p. 118).

Strategic communication is sometimes reflected in changes in the terms used to refer to dementia or Alzheimer's disease. Examples can be found in relation to professional medical authorities, governments and Alzheimer associations. For example, according to Kennedy (2010), the latest changes in the classification of various forms of dementia in the Diagnostic and Statistics Manual (V) of the American Psychiatric Association, were in part to avoid "the stigma associated with dementia when categorising deficits among younger people with progressive cognitive decline associated with HIV or traumatic brain injury." Such concerns seem to reflect a belief that dementia is stigmatizing because it is perceived as being a condition of older people and not that it is a label which is perceived as discrediting to all people with dementia.

In Japan, the term for dementia was officially changed in 2004 from a term signifying a "disease of cognition associated with idiocy" to one signifying a "cognitive syndrome". This strategy was accompanied by an educational initiative and awareness-raising events which, it is claimed, resulted in the term being widely accepted. Whilst a new term is unlikely to change the underlying perceptions of the disease or condition which it designates, Miyamoto et al. (2008) suggest that there had been a growing awareness in Japan, based on people with dementia speaking out about their experience, and that the old term did "not accurately depict the reality of the condition" as they had come to understand it. This highlights the importance of hearing the voices of people with dementia. It also highlights the complexity of strategic communication in that it not only seeks to achieve certain goals but may also be the result of changes in the way that dementia is perceived.

In Finland, the Finnish Association, which represents people with memory disorders and their carers, changed its name from one which included the term "Alzheimer" to "Muisti" which means "memory" and in so doing established a broader focus, covering memory-related disorders. However, this focus on memory disorders was only partly in response to concerns about stigma as it was partly influenced by the development of terminology which accompanied the development of memory clinics. Again, whilst strategic, it was influenced by changes within society in Finland and was in keeping with the joint objective to create a "memory-friendly Finland" on the basis of four pillars:

- “to promote brain health,
- to foster a more open attitude towards brain health, treatment of dementia and rehabilitation,
- to ensure a good quality of life for people with memory disorders and their families through timely support, treatment, rehabilitation and services,
- to increase research and education.”

Finally, the terms “carer”, “caregiver” and “informal carer” are used in English-speaking countries and in the international literature on dementia to denote people who provide care on an unpaid basis to a person with dementia. Usually, carers (or caregivers, informal carers etc.) are relatives, partners or close friends. Some do not view themselves as carers or feel that they provide care. Some feel that they provide more care than they would like to provide, have no training, are not formally recognised and were more or less forced into the role of carer (Alzheimer Europe, 2001). It has been suggested that the term carer promotes unskilled and cheap forms of care for people with dementia (Cheston and Bender, 1999). The emphasis on the term “carer” implies that most people with dementia are already cared for (i.e. they must be as they have a carer). A whole range of services and support, which the person with dementia needs, can be considered as being provided and at little or no cost to the state. It is therefore possible that the term carer is sometimes used strategically to position the relatives and close friends of people with dementia in a way which reflects and may even serve to justify the official discourse of the state with regard to healthcare provision. On the other hand, the term might also sometimes be chosen in recognition of the fact that not all relatives are carers and vice versa.

### **Related ethical issues**

#### *Judging the motives and morality of strategic communications*

We define “strategic communication” as ways of communicating about dementia which result from a strategy or are intended to accomplish a specific goal. Strategic communication about dementia could perhaps be described as good or bad, depending on what the specific goal is. However, it is likely that some forms of strategic communication might be considered as more defensible than others and that some might be considered as “misguided”.

With reference to the biomedical model of dementia, Ballenger warns against the assumption that a particular portrayal of dementia should be rejected or criticised solely on the grounds that it is ideologically driven. He suggests, on the contrary, the importance of considering the moral and practical implications in the concrete situations in which it is deployed, including the political and policy ramifications resulting from research or a focus on a particular explanatory model of dementia. In this sense, one might say that the end result, in terms of implications, particularly for people who have or will develop dementia, is one of the most important factors in trying to determine whether a strategic communication is ethical.

#### *The efficacy of strategic communication*

Strategic communication is complex and it is sometimes difficult to say with certainty whether a goal has been achieved (which may or may not be ethical). It cannot be determined with any degree of certainty, how a particular message or portrayal will be received and interpreted by the targeted audience. Sometimes, a particular well-chosen reference

to a dementia-related issue may contain a second message through the choice of metaphor or terms used. For example, Terry Pratchett stated,

*“What is needed is will and determination. The first step is to talk openly about dementia because it’s a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name”. (Alzheimer’s Society, 2008)*

The message seems clear and the author clearly described the link to folklore. However, the symbolism of the demon may be counter-productive in that it reinforces the fighting metaphor and may contribute towards the identification of people with dementia as “other” and to fear, based on the common belief that a person can be possessed by a demon. Strategic communication may sometimes backfire or have unexpected results, which are not in the interests of people with dementia, particularly if it becomes distanced from its original context.

In some countries, awareness-raising campaigns about dementia and organisations (such as the Finnish Alzheimer Association) which focus on memory-related problems may have been helpful in raising awareness about the difference between natural ageing and AD. However, people experiencing different kinds of symptoms (e.g. mood changes, confusion and paranoid delusions) might not recognise a possible link to dementia and even if diagnosed, might not feel that services and support for people with a memory-related disorder are appropriate for them.

An issue for which there are differences of opinion as to what would be beneficial is that regarding official changes to the term “dementia”. As dementia is the recognised term for a medical condition, a change of term would just be a new word for the same condition which retains the same meaning. The terms used to denote other conditions such as schizophrenia and leprosy have been changed in some countries and there have been studies which have explored the impact of using more politically correct labels for schizophrenia. There is little evidence of this having had a significant impact on the way that those conditions or the people with those conditions are perceived and in some cases may even have a negative impact (Chung and Chan, 2004; Penn and Nowlin-Drummond, 2001). It may take more than a new word to change public perceptions of diseases such as schizophrenia, leprosy and dementia as they are deeply rooted concepts which are not defined merely by the labels attributed to them. Ballenger (2010) further links the negative impact of the term “dementia” to normative standards of productivity and competence, which drive the stigmatization of ageing and cognitive impairments. He concludes that changes in terminology are merely euphemistic and that euphemisms “allow us to ignore unpleasant realities and shirk difficult social and cultural work”.

*“Positioning” people with dementia in relation to other people and society*

The strategic use of certain terms, perhaps over a length of time and by experts and official or professional bodies, may, depending on the context, be perceived by the general public as the correct terminology or as reflecting an undeniable “truth” or “fact”. If people with dementia are portrayed in a positive light, the impact may be beneficial but when this is not the case, it may be difficult for them to free themselves from the connotations and meanings associated with various terms or portrayals. They may be placed in a symbolic position in relation to others and society (e.g. as a patient rather than a person, as a recipient of care rather than a partner and as a burden rather than a tax payer who con-

tributes towards the care of other members of society) from which it is difficult to extract themselves. This may also be the case for carers. Cheston and Bender describe the consequences for relatives and friends of being defined as carers:

*“Being reduced to the role of carer removes at a stroke their relationship with their spouse or parent and its years of history; and, having stripped away all the spoken and unspoken “theres and thens”, allows only the “here and now” of organic brain damage to be considered.” (Cheston and Bender, 1999, p.94)*

They also describe the situation whereby some people do not fit into the positions and roles to which they have been ascribed and insist on “acting as if they were still important people, people of value and worth who should be respected even if they did have some memory problems” (Cheston and Bender, 1999, p. 176). This calls for reflection on what we are implying, taking for granted and accepting when we use such terms.

## **The person with dementia**

Having looked at how people understand dementia in terms of its cause or origin, how they talk about dementia and people with dementia and what this suggests about their attitudes, expectations and feelings about it, we now explore different ways in which the existence and experience of dementia are perceived and portrayed.

In the first part, we will look at perceptions that deny people with dementia a particular status:

- personalism,
- dualism – the “mind-body split” and
- dementia as a “social death”.

The second part regards perceptions that focus on fundamental changes within the person:

- becoming a different person/a stranger,
- loss of self.

### ***Personhood***

Personhood is defined in the Oxford English Dictionary as “the quality or condition of being an individual person” and defines a person as “a human being regarded as an individual”. Taken together, these definitions imply two criteria for personhood: 1. to be a human being, 2. to be regarded as such by other people.

### **The criteria for human status**

For some people, the human quality is linked to spiritual beliefs about people having a spirit, a soul or a kind of unique inner essence, which in some religions is believed to continue beyond human life. A distinction can also be made between qualities that are possessed and may be lost (so the person is incomplete) or qualities which are constantly being constructed. In other words, personhood could be viewed as a kind of inner essence, which in the course of the disease is eroded and finally lost, or on the contrary, as something which is constantly being constructed within a social context (Swane, 1996). This

essence of what makes a person human has also been described in terms of the “true self”, the “living spirit” and “essential humanness” (terms cited in Ballenger, 2006).

According to Buron (2008), there is little disagreement that people with dementia are entitled to personhood status at the human biological level. However, Dan Brock (1993) argues that people with severe dementia, whilst members of the human species are worse off than animals in some respects in that they have no capacity for integrated and goal-directed behaviour and that due to memory loss cannot forge links across time that establish a sense of personal identity across time. He concludes that they lack personhood (Baldwin and Capstick, 2007). The importance of having an awareness of oneself in the past (Buchanan, 1988) or of some memory of psychological continuity over time (Parfit, 1984) has been suggested. Buchanan (1988) claims that when people reach a stage where they have not only lost all connection to their former self but also any kind of continuity with people in general, they are non-persons. Similarly, Kuhse (1999) considered personhood as being dependent on having a perception of existing over time and having a vision of one’s life as extending into the future, as well as possessing certain capacities. By contrast, others have focused on demonstrating that even those with advanced dementia who are unable to care for themselves or communicate easily have a certain level of awareness (Clare et al., 2008). Sabat (2002), using the tri-partite model of self, argues that people with dementia continue to have a sense of self as illustrated by their use of the indexical ‘I’.

There is a tendency to concentrate on instrumental reasoning capacity and accurate memory rather than the more social, expressive, imaginative and even unconscious dimensions of being human (Crisp, 1999). Kant, for example, emphasised the necessity of possessing rationality (the ability to think and reason logically) and being able to communicate this to other people to qualify as a person. The term “hypercognitive” is often used to describe this bias in the importance attributed to cognitive faculties in defining personhood (Post, 1995). Crisp does not deny the loss of cognitive faculties but rather emphasises the importance of how people view being human and the self. In some of the portrayals of famous people who had dementia, it is the loss of their intellectual capacity resulting from dementia which is often portrayed as most tragic, as if their other human qualities were of less importance. One tabloid newspaper wrote an obituary about Iris Murdoch with the following headline and caption:

*“Brilliance dimmed by disease: Philosopher and novelist who fell from flights of genius to watching the Teletubbies.” (Sharp, 1999, cited in Kirkman, 2006)*

### **Being considered a human being by others**

Kitwood stated, “In an ethical sense, personhood is attributed even to the new-born infant. In an empirical sense, personhood emerges in a social context” (Kitwood, 1992, p.275). He described personhood as “a standing or status that is bestowed on one human being by another in the context of relationship” (1997, p.8). Kitwood challenged the capacity-based view of personhood and the bio-medical approach to dementia and suggested that people with dementia retain a personal awareness of their individual uniqueness of being until death.

Although people with dementia, like everyone else, have an individual uniqueness, this may at times be overlooked in that the overriding emphasis is placed on the fact that they have dementia. One person who has dementia described the mere diagnosis of dementia

as like being certified as a non-person (Thompson, 2008 in Nuffield Council on Bioethics, 2009). Price (2008) describes how once diagnosed with dementia, “the diagnosis and its presumed personal and public consequences somehow become a person’s chief defining characteristics” (2008, p.1341). This, she attributes partly to the emphasis on the medical model of dementia. This observation was made in the context of a discussion about the invisibility of gay men and lesbians with dementia and how they have been conspicuously absent from dementia research, policy and practice, but it could equally apply to all people with dementia. The overriding focus on dementia can be likened to the concept of identity engulfment described by Jones et al. (1984).

Aside from philosophical and ethical arguments about the criteria for being considered a person, the use of metaphors by lay people for people with dementia provides additional insight into how people with dementia are sometimes perceived as non-human (please see section on metaphors for more details). In the qualitative study by Corner and Bond, one person commented that all that could be done for people with advanced dementia was to provide basic care and ensure that they were “well fed, and watered, and clean” (2004, p.151), which has connotations of caring for an animal or plant. In another study, a person with dementia was described as someone who was sitting there like a vegetable (Devlin et al., 2007). From the perspective of a person with dementia in a psycho-geriatric unit, the behaviour of staff in serving food was likened to tossing food to a dog (Edwards and Nordvall, 2008). The perceived absence of personhood is even more explicit in the following quotes:

*“But you have to remember that body is not who the person is. The person is gone.”*

*“There’s no point in asking her...she’s not there, as far as that part of her.”*

*“I wasn’t dealing with a human. Isn’t that a terrible thing to say? I wasn’t dealing with a human being.” (Dunham and Cannon, 2008, p.49)*

*“He possesses neither sensitivity nor affect, neither language nor thought. He has lost all humanity. He is no more than a body.” (cited in Ngatcha-Ribert, 2004, p. 57 – our translation)*

### **Dualism – the “mind-body split”**

The metaphors mentioned earlier which reflect a perception of people with dementia being absent or empty reflect dualism as the implication is that the person’s body is there but their mind is not. It is as though the physical body is just a container of the mind. The “real person” is believed to be found in the mind. This was also discussed in the section on personhood.

Dualism is the term which reflects the idea that there are two fundamental categories of things or principles (Robinson, 2012). When applied to the philosophy of the mind, it typically involves a perception of the body and the mind as two separate entities with one represented by something physical such as the brain and the other being detached from chemical or physiological processes, having a source and essence of its own (Hinshaw, 2007). In line with this philosophy, people could perhaps be described as encompassing a container (such as the physical body, including the physical brain) as well as a separate, non-physical mind, spirit or soul (AllAboutPhilosophy, 2013). Dualism can be traced back to the ancient Greek philosophers but the current, everyday use of this term tends to mainly

reflect the work of René Descartes. He associated the mind with consciousness and self-awareness rather than intelligence which was associated with the brain (Wozniak, 1995). However, it is not clear how lay people interpret the term “the mind” and whether their use of the term always reflects this mind-body dualism. Dictionary definitions of mind include entries which refer to the brain

*“The human consciousness that originates in the brain and is manifested especially in thought, perception, emotion, will, memory, and imagination.” (The American Heritage [online] Dictionary of the English Language)*

Moreover, the terms “mind” and “soul” are sometimes used interchangeably. They were both used by the ancient Greek philosophers and Descartes but the term “soul” may be linked nowadays to a more theological understanding of a non-physical matter than the term “mind”.

It is not always clear when people use the term “mind” whether they are referring to the workings of the physical brain or that which is non-material. Nevertheless, most references to the loss or absence of a mind in relation to people with dementia do seem to suggest mind-body dualism.

In their work which identified frames and counter-frames for dementia, Van Gorp and Ver-cruysse (2011) identified mind-body dualism as the most common conceptualization of dementia. These frames were derived from an analysis of numerous portrayals of dementia in the media. They proposed a counter-frame of unity of body and mind which involves putting the mind and body on an equal footing.

Merleau-Ponty developed a concept, based on Heidegger’s notion of Dasein (being-there), which is now often referred to as the body-subject. This implies that every human has a body (being a physical creature) and is capable of thought, reflection and communication but these two parts are not separate as in Descartes’ body/mind dualism but rather a unified form which experiences the world and expresses itself in a bodily form (Matthews, 2006). When a person sees, s/he is dependent on the eyes but there is an “I” behind the eye. As dementia progresses, the person can no longer rely on the unified form. Consciousness is expressed through bodily activity but the body, as a vehicle for expression, is breaking down (Matthews, 2006). This does not mean that there is no consciousness. At a more psychological than philosophical level, Jenkins and Price (1996) draw attention to the way that people tend to make analogies between their bodies and elements or aspects of everyday life (e.g. viewing their body as a home, servant or vehicle). When the body starts to let the person down and the unified form fails to function, the body might, for example, be seen as a traitor, an enemy or a prison.

Most perceptions of dementia reflecting dualism emphasise a living body without a mind. This is sometimes linked to a particular mode of existence, namely a living death as demonstrated by the following quote:

*“with the number of people who are over 65 increasing significantly each year our society is today finding itself faced with the problem of keeping a large share of its population from joining the living dead – those whose minds are allowed to die before their bodies do.” (Kaplan, 1953 cited in Ballenger, 2008, p.500)*

### **A “social death”**

Dementia is often described as a “social death”. A social death is understood to mean “as good as dead” and that the person concerned has been discounted in social terms (Sweeting and Gilhooly, 1997). It has also been defined as “a situation in which there is absence of those behaviours which we would expect to be directed towards a living person and the presence of behaviours we would expect when dealing with a deceased or non-existent person (Kastenbaum, 1969, p. 15). The concept of dementia as a social death is closely related to other concepts of relevance to the way that dementia is perceived and portrayed such as the mind-body split, loss of personhood, lack of quality of life and the metaphor of the empty shell which are discussed elsewhere in this report. The term now seems to be fairly widespread, with such references being made in novels, the media and films, and even by healthcare professionals (Kirkman, 2006).

The term is not limited in use to people with dementia as different groups of people are at risk of being perceived as socially dead. These include people with a lengthy fatal illness, the very old and those suffering from a loss of personhood. Sweeting and Gilhooly (1997) point out that these three characteristics (i.e. old age, fatal illness and loss of personhood) are commonly associated with people with dementia. They carried out semi-structured interviews with 100 carers of people with dementia to explore their perceptions of dementia as a social death, and applied post-interview ratings based on their observations of the carers and on the carers’ responses. The findings revealed that just over a third of carers believed and behaved as if the person with dementia were socially dead. One of the carers in this category stated:

*“... it really dawned upon me that my mother was gone, that this person wasn't my mother any more. It's hard – really the person has died and you're just left with the body, that's how I feel about her... the realization hit me that night – I was talking to her and she wasn't there – and I cried all the way home. I thought “My mother is dead”. (Sweeting and Gilhooly, 1997, p. 104)*

One third of carers were rated as neither believing nor behaving as if the person were socially dead and one fifth of carers as holding this belief but not acting as if the person were socially dead. A small number of carers behaved as if the person were socially dead but did not perceive them as such. It should be noted that neither Sweeting and Gilhooly nor any of their participants used the term “social death”. The ratings of perceptions of dementia, which the researchers grouped together under the term “social death”, were based on responses to questions about perceived consciousness and contact with the environment, the continued importance of the person's dignity, anticipation of the person's “biological death” and the value of their life. Observations of behaviour were also made such as the extent to which carers ignored or paid attention to the person with dementia, attended to him/her and included him/her in activities, and acted in accordance with his/her wishes. Numerous associations were noted between the characteristics of the carer and the person with dementia, and various perceptions contributing towards the perception of a social death. The likelihood of carers behaving as if the person with dementia were socially dead was found to be higher when the person with dementia did not recognise the carer, when s/he behaved in ways which carers found challenging and when the current and premorbid relationship between the person with dementia and the carer was reportedly poor (Sweeting, 1991).



### **Related ethical issues**

#### *Personhood and human dignity*

If, at any stage of the disease, people with dementia are not accorded the basic biological status of human being or their inherent or socially acquired personhood is not recognised, there is a risk of failure to respect their human dignity and failure to treat them with the same level of respect and care as that given to other people. This risk is heightened in today's society which places great emphasis on cognition and tends to root selfhood and personhood in cognitive abilities, especially language, rationality and memory, with little attention being paid to emotions (Ballenger, 2006; Post, 1995). This may result in objectification and affect quality of life. Poor care may include failure to respect privacy, inadequate nutrition and pain management, stigma, abuse, lack of consideration for their relationships to other people and their known wishes, failure to communicate, and failure to provide human contact and reassurance.

Whereas Kitwood considered that personhood (as something that is transcendent, sacred and unique) led to an ethical obligation to "treat each other with deep respect" (Kitwood, 1997, p.8), he was also aware that the personhood which is socially bestowed on a person could be withheld and that people with dementia might find that personhood which was attributed to them at birth being eroded either in the social context (e.g. through malignant social psychology) or as a result of social exclusion. He described this as having a potential negative effect on their personhood and wellbeing but also contributing towards a further deterioration of their condition. Arguing in favour of the perception that people are embodied agents who act and interact within a particular cultural and historical context, Hughes (2001, p. 91) suggests that undermining the personhood of people with dementia amounts to "an undermining of our own standing as persons amongst persons".

#### *Social exclusion*

Many people with dementia lack (to varying degrees) the necessary capacities to engage socially and effectively with others. Communication becomes problematic as dementia progresses and people with dementia may withdraw from social contact. At the same time, other people may distance themselves from them, thereby resulting in isolation and social exclusion. In Kitwood's spiral of dementia, he emphasised how the loss of personhood was related to neurodegeneration, isolation and ultimately, death. The cognitive approach to personhood is a very individualist/rights-based approach and does not address the socially constructed nature of personhood or perceptions of innate personhood (Kitwood, 1997). It offers no hope for people with severe cognitive impairments to retain their personhood and places responsibility for fulfilling the criteria for personhood solely with the individuals concerned. It does not recognise the responsibility of other people to facilitate communication and interaction or to support various capacities. This is not the case with infants who nevertheless start out in life incapable of meaningful, verbal communication.

The perception of people with dementia as being absent or socially dead may also contribute towards social exclusion and isolation as relatives and carers will not make the necessary effort to communicate, based on the belief that it is pointless as the person is "not there". Such reactions towards the person with dementia may have a negative impact on care, which according to Kitwood (1997) may contribute towards a downward spiral marked by a deterioration in the condition of the person with dementia. According to Stirling (2010), who was drawing on the principles of 'social role valorisation' (Wolfensberger,

1998), persons with dementia deserve to be not only treated with respect but to live in our midst and be valued so that we can learn from them how to live well with high levels of impaired ability.

#### *Survival and care*

Mind-body dualism is not just about separation. It represents a dialogue of loss and the loss is linked chiefly to the loss of the mind. In today's Western society, the body may be important in relation to the emphasis on youth, the dislike of signs of ageing and the cultural rejection of perceived ugliness but the mind is valued in terms of identity and personhood. There may be an assumption that a body without a mind is no longer a human being (Van Gorp and Vercauysse, 2011). This also fits in with the concept of social death, whereby the person is perceived as being socially dead even though the physical body lives on. Both ways of perceiving people with dementia may have serious consequences when it comes to making life and death decisions in life-threatening situations.

Emphasising the importance of cognition may also endanger the existence of people with dementia. Drawing on Kant, Cooley (2007) suggested that people with dementia had at some point a moral duty to commit suicide in order to preserve their moral self and not become a burden on society. Whilst this is a radical perspective which few people might accept, similar reflections might nevertheless influence end-of-life treatment decisions by healthcare professionals, relatives and people with dementia, notably involving the withdrawal of food and liquid.

The perception of people with dementia as being "socially dead" may lead to inadequate care at the end of their lives. This fails to respect their right to the same quality of care and treatment that other people receive. Perceiving dementia as a social death may fuel the process of depersonalization, withdrawal and social alienation, which Kitwood described as contributing towards the actual death of the person concerned, and which may also reinforce the out-group status of people with dementia, therefore reinforcing their stigmatization.

The concept of a social death has been linked to people with dementia being perceived as "sufferers", lacking insight and being unable to articulate their situation, although this has started to change in the last few decades due to the increasing focus on personhood (Bartlett and O'Connor, 2007). Just as Kitwood highlighted the threats to personhood, his work also emphasised the need to be aware of personhood, of the psychological needs of people with dementia. He drew attention to need to explore and use different methods of interaction e.g. including validation and facilitation. Much of the positive work and ethical approaches to dementia care which have developed in the last two decades are firmly grounded in the recognition of personhood and in holistic/inclusive perceptions of dementia.

#### *Coping strategies*

Sweeting (1991) found that the perception of dementia as a social death was often not associated with behaviour towards the person with dementia as if s/he were dead. It is possible that the perception of dementia as a social death may serve as a coping strategy for some carers, enabling them to carry on providing care and at the same time protecting their own emotional and psychological wellbeing. For some people, anticipatory grieving for various losses may be a coping strategy to enable carers to move on and adapt to changes in the person with dementia. Such grief does not rule out the maintenance of a

relationship with the person with dementia. It may reflect acceptance of changes in the person's behaviour and a less rigid understanding of personhood.



In the remainder of this section, we look at perceptions which do not deny the person status of people with dementia or their status as a living human being, but which focus on fundamental changes within the person and to some extent may reflect a perception of a mind-body split:

- Becoming a different person/a stranger,
- Loss of self.

### ***Becoming a different person/a stranger***

People often have a feeling that a person with dementia is not the person they once were, even though they are still a human being and alive (Ngatcha-Ribert, 2004; Walters et al., 2010). Some carers have described the emotional pain they experience when their relative or friend with dementia no longer recognises them and no longer reacts/interacts as they used to in the past. Perceived difference may be related to the person with dementia forgetting shared memories of the past, communicating in a different manner, changes in emotions, expression, interests and physical appearance and style, and failing to recognise familiar people. Although people with dementia can often remember things that they experienced or did many years ago, many will forget significant aspects of their own (recent) history.

In the context of perceptions of somebody not being the same person, sometimes the focus is on the loss of their perceived essence as a person (e.g. spirit, soul or mind) and the replacement of that with the essence of another person. This may reflect body-mind dualism as it may be presumed that the former mind has been lost and replaced by another with the result that the person is now, for all intents and purposes, somebody different. This is sometimes described in terms of a stranger.

*"[Alzheimer's] robs not only the person who has it but the family members – their memories of who that person was are threatened to be replaced by the stranger who comes to live in that body." (Leeza Gibbons, cited in Basting, 2009, p.40)*

Sometimes, there may be a belief that the person is, technically speaking, the same person but that they are no longer the person with whom one had a unique relationship. In this sense, becoming a different person would be a figure of speech based on the perceived radical change of personality and of the way that a person with dementia is experienced by other people.

*"I guess from a person who's looking at the person with dementia, it would be their essence maybe that might have changed and they don't respond to you as they would have before, they don't interact with you as they would have before. So I guess the essence of that person has changed to a certain extent. OK, yes that person, you know is my mum, is my dad, is my brother but they don't actually recognise me, they don't recognise where they are. So I guess from my point of view, I would probably find the person different, yes. Although, yes, that person is my mum, my dad, whatever, they are no longer the same. (Gove, 2012, p.261)*

Another way to explain the perceived changes in the person with dementia is as a process of becoming strangers. Here, there is no question that the person is not the same person. Rather the emphasis is on a gradual process of emotional and physical alienation whereby the relational ties with the person deteriorate to such an extent that the person becomes like a stranger. In a Canadian study involving 15 carers this was described in terms of “dimensions of becoming strangers” (Wuest et al., 1994). Other carers have described a process of detachment and “drifting away” but Graham and Bassett (2006) point out that perceptions of togetherness as opposed to detachment may differ between the parties involved. The person with dementia, who is perceived by the carers as being detached, may actually perceive him/herself as being very much involved but this is not interpreted as such by the carer.

On the other hand, there are frequent reports of people with dementia not recognising their relatives, partners and friends. The following extract describes a carer’s fear of a possible future mutual lack of recognition whereby she would consider her husband a different, new person and he would literally not recognise her.

*“You are destined to live only with the memory of who he was. How can you say goodnight to your sweetheart and wonder, will this be the night from which reason will never again waken? Will morning find that new person in my bed, the man who will not know who I am or why I am in his bed?” (Davis, 1989, p.140 cited in Oppenheimer, 2006)*

### **Loss of self**

The “self” amounts to more than being a person. In keeping with the belief that the mind is something that can be detached from the physical person, and that somebody can become a different person, many people perceive dementia as leading to a loss of self (i.e. of being aware of oneself as a particular person with a particular history). Kitwood (1997, p. 15) stated,

*“Each person has come to be who they are by a route that is uniquely their own; every stage of the journey has left its mark.”*

Beliefs about how the self can be lost tend to be closely related to beliefs about what constitutes the “self”. As with personhood (i.e. what makes us a person and leads to others considering us as such), the self is often understood as being closely linked to beliefs about the role of cognition and autobiographical memory (Fazio and Mitchell, 2009). Kitwood (1997) also emphasised the importance of meaning making, of how people make sense of situations and of the self being constructed through interaction with others, resulting in the deployment of learned resources for action. Drawing on social constructivism, Sabat (2001) describes three types of self: the self of personal identity (usually presented in the form of information relating to I, myself, me, etc.), the self of mental and physical attributes and the self which is presented to the world (a kind of presented self or persona). Speaking about identity and selfhood, Snyder suggests that it is in the context of the constant, on-going exchanges between people, involving verbal and non-verbal communication, that

*“we define ourselves and express that selfhood in the act of being acknowledged and understood by another. In this light, interpersonal communication is a mutual co-constructed process in which each person offers definitions of self and of what is real for others to interpret, affirm or challenge.” (Snyder, 2006, p. 259)*

The presentation of various selves through interaction and communication with other people gradually becomes problematic for many people with dementia. People with dementia may eventually have difficulty communicating their selves and other people may have difficulty recognising those selves. According to Sabat and Harre (1992), the externally defined self is more susceptible to decline as a result of dementia than the internally defined self. They suggest that other people may contribute towards what they then perceive as a loss of self through the way that they view and treat people with dementia (Sabat and Harré, 1992).

Despite the common perception of the loss of self, several researchers have reported evidence of a persistence of self in spite of considerable cognitive impairment (Clare et al., 2008; Fazio and Mitchell, 2009), including both the internal and external self even amongst people with severe dementia (Small et al., 1998). The concept of the self is often a reflection of the way that one is perceived by others (Mead, 1934) as the perceptions of others may be internalised and affect self-perception. In one study, people with dementia described themselves as being “lesser people” after diagnosis and as belonging to a more marginalised and devalued group. One person spoke of his desire to protect his reputation and avoid being looked down on (Katsuno, 2005). This suggests a tendency to anticipate the reaction of other people based on one’s own beliefs about how dementia is perceived in society, which highlights the importance of reflecting on the way that dementia is currently perceived and portrayed.

### Related ethical issues

#### *The meaning of becoming “a different person”*

There are philosophical debates as to the criteria for being a person and the factors which might justify the claim that somebody is no longer the same person. McMillan (2006) highlights the difference (in philosophical debates) between numerical and qualitative identity. He uses two examples for which it is necessary to imagine that he deliberately and secretly changes a lectern the night before it is to be used in public. In the first example, he paints it yellow and in the second example, he changes it for an identical-looking one. The yellow lectern, he explains, represents a qualitative change in that people who had seen it before might recognise that the qualitative identity of the lectern had changed. The apparently identical, but actually completely different, lectern might be mistakenly perceived as the being the same, but the numerical identity of the lectern would have changed. McMillan expresses the view that “folk notions of identity focus more upon “qualitative” identity or the features that a person has” (2006, p.63). In the context of discussions about the ethical implications of perceiving somebody with dementia as a different person, it is therefore important to avoid taking statements too literally, and to recognise that these may be themselves metaphorical ways of describing drastic changes. Indeed, Lesser (2006) suggests that if people really believed that the person they loved had gone away and been replaced by another, it would be easier to accept than the belief that the person was still there but unable to recognise them or to continue the relationship with them.

#### *Relationships and the responsibility for care*

Being perceived to have become a different person or a stranger has implications for issues related to care ethics such as the importance of relationships, a person’s unique identity and their personal history. Within the context of person-centred care, the focus is on the person with dementia as a unique individual and on his/her unique needs and wishes. For

professional carers, changes in the person with dementia, even fairly dramatic changes, may be less important as they did not have a prior relationship with that person and in part, as they are paid to care. For informal carers the situation is somewhat different as they are providing care to a specific person because that person is who s/he is (i.e. not because it is their professional duty to do so). The relationship and how it has evolved over time is therefore important to their dedication, motivation and in some cases to their sense of obligation to care for that person. People may feel less inclined to care for a stranger or for someone who no longer recognises them and, as with perceptions of dementia as a social death and in connection with the loss of personhood, this may represent a threat to their survival.

#### *Changes in the nature and quality of relationships*

The perception of the person with dementia as a stranger may have a negative impact on relationships, especially between couples, as the shared past, planned future, common values, commitment and many of the important things which held the relationship together and made it meaningful, might appear to have gone. In addition, the feeling that the person with dementia has become a different person or a stranger may lead an otherwise faithful partner to engage in a relationship with someone else. Depending on one's moral and religious views, this may be considered by the people concerned and others as positive (enabling the partner who does not have dementia to benefit from a meaningful relationship and perhaps continue to care for the person with dementia) or negative (e.g. immoral and unfair, perhaps leading to a total breakdown of the existing relationship with implications for the continued provision of care).

Perceiving the person with dementia as having no concept of self or as a different person may result in a gradual withdrawal of social investment in that person. Relatives and friends may communicate less with the person, involve him/her less in activities, visit less and behave towards him/her in a different manner, one which attributes little in any importance to his/her preferences, habits, idiosyncrasies, past life and established relationships. This may limit the possibilities for the person with dementia to define and express his/her self as that self is not recognised and taken on board. This would have implications for his/her wellbeing, the maintenance of relationships and the provision of person-centred care. On the other hand, Luntley (2006) suggests that even if the self were considered as having been eroded, the person with dementia could still be considered as "an object of moral concern" as s/he would still be a subject capable of experiencing pain, distress and a range of human emotions.

#### *Existential fear and isolation*

Perceptions of dementia leading to a loss of self may nevertheless contribute towards people not wanting to seek a diagnosis but also, if diagnosed, to fears about the experience of dementia that lies ahead. Fears about a potential loss of self may also be linked to an interest in self-preservation and to a deep-seated fear of existential isolation and meaninglessness (Yalom, 1989). Relationships may change, people may come and go but you have/are yourself. The fear of losing one's self implies total isolation in which existing and even potential relationships with other people which provide meaning and connectedness, would be meaningless, as would goals and hopes, as the person is no longer him/herself but already an unknown other person with whom one has no connection or vested interest.

Perceptions reflecting the possibility of losing one's "self" are often fairly black and white – you either lose it or you don't, and some people believe it is just a question of time as to when you lose it. Markus and Nuriou (1986) have proposed the concept of possible selves which focuses not only on current knowledge or perceptions about the self but also on hopes and fears about how or what a person would like to become. Cotrell and Hooker (2005) explored various perceptions of hoped for and feared selves of people with AD and came to the conclusion that the construction of such selves often reflected adaptive responses to dementia. Whilst over half of participants with AD in the study reported well-developed dementia related selves, many mentioned non-dementia related selves. Many "hoped for" selves were mentioned and those linked to the domain of the family were linked to affect which emphasises the importance of social and familial ties. The concept of possible selves creates a more balanced, flexible and dynamic approach to perceptions of the self, and avoids an over-emphasis on loss. Were this to become more commonplace, the fear linked to a loss of self might gradually lessen. However, Cotrell and Hooker (2005) suggest that the prospect of cognitive impairment is so threatening that people do not tend to construct such selves in advance. Ironically, the perceived loss of self may be part of what makes dementia a frightening prospect, which suggests the need for greater awareness about how people experience and cope with dementia.

### The characteristics/attributes associated with dementia

In this section, we focus on perceptions of what people with dementia are like. For example, what do they look like, and how do they act and react within society. More specifically, we will explore images/mental representations and stereotypes of dementia, the way that people with dementia are often perceived as unwilling or unable to reciprocate and finally, perceptions related to vulnerability, dependency and burden. The first topics are therefore:

- Images/mental representations of dementia,
- Stereotypes.

#### *Images/mental representations of dementia*

The images or mental representations that people have of dementia may be based on people with dementia they have encountered and even cared for. Some may be composite images, made up of what they have heard or believe about dementia, based on their exposure to various cultural portrayals of dementia within society and resulting from their interaction with other people. There is perhaps a tendency to focus on images which are more representative of fairly advanced dementia (e.g. with references to difficulties eating and communicating, maintaining personal hygiene and difficulties with continence). This could be because physical signs of dementia are more visible in the later stages, that such images are particularly disturbing and socially salient and hence retained, or due to the stereotype of dementia being the advanced stage (see next sub-section on stereotypes).

*"It's as though that's it, you are dribbling and nodding, and that's Alzheimer's. That's the picture of Alzheimer's. But we are sitting all here talking perfectly normally. We have got Alzheimer's of some form, we are not nodding and dribbling" (a person with dementia) (Alzheimer's Society, 2008, p.45)*

*"One day I came in and saw her... what can I say... everything around was messy she was messy, disgusting... as a person from the slums, filthy, dirty, totally soiled." (an informal carer) (Werner, Goldstein and Buchbinder, 2010, p. 162)*

With regard to people with mild dementia, references have been made to behaviour and to subtle facial signs such as a look in the eyes which suggests that a person is confused or not following the conversation (Gove, 2012). The limited information about the way that people with mild to moderate dementia are visually perceived may also be linked to the way that people with dementia and their relatives and close friends often deliberately or otherwise try to hide any signs of dementia. This may be part of the process of coping with dementia (e.g. keeping up the pretence of good health or denial of the condition) and has also been linked to the consequences of dementia being perceived as a stigma (Blum, 1991; MacRae, 1999; Werner & Heinik, 2008). In MacRae's qualitative study involving semi-structured interviews with carers, a high degree of collusion between people with dementia and carers was observed, especially between spouses.

The images that people have of dementia may be gradually changing as people with dementia are increasingly talking openly about their experience of dementia, explaining not only what it is like to have dementia but also showing by their presence and by communicating with other people what dementia "looks like". In many cases, people with dementia do not have a perception of themselves as being dramatically different from other people in the sense of looking, feeling or acting differently.

*"I've heard people say "You don't look like you've got dementia", fancy that! How are we supposed to look?" (Devlin, MacAskill and Stead, 2007, p. 52)*

*"I don't really feel anything really. I mean I feel now as I did five or ten years ago. I am doing all sorts. I can drive. I mow the garden. I can decorate." (Alzheimer's Society, 2008, p.45)*

When symptoms of dementia become more or less apparent, they are counter-balanced by numerous other aspects of a person's personality and behaviour, provided that people do not focus only on the symptoms of dementia. However, similarity does not stand out and is therefore often disregarded. Moreover, members of the European Working Group of People with Dementia have reported cases where a diagnosis of dementia has been called into question on the grounds that the person concerned "appears too normal". This suggests that negative images of dementia are sometimes so strong that a more positive image is considered inaccurate.

### ***Stereotypes of dementia***

Stereotypes are attributes/characteristics which are assigned to groups of people who share another attribute which is socially salient. Examples include the belief that girls are not good at maths (Cvencek, Meltzoff and Greenwald (2011) and that obese people are lazy, unmotivated, and lack self-discipline (Carels et al., 2013; Puhl and Heuer, 2009). They can also be understood as simplified mental images. It may be difficult to differentiate between people's knowledge about the symptoms of dementia and possible stereotypes. Some symptoms or perceived experiences of dementia may be mentioned as they are the ones which people find most disturbing or striking, and not necessarily because people think that they are applicable to everyone with dementia. People are often unaware of the stereotypes they hold and may have implicit stereotypes which differ to what they explicitly believe (Scholl and Sabat, 2008). These implicit stereotypes can be uncovered by subliminal exposure to stereotypical words but this procedure is not widespread in studies which explore people's perceptions of dementia. The following sub-sections highlight a few common stereotypes.



### *Negative stereotypes*

Although positive stereotypes exist, stereotypes ignore diversity within groups and are therefore often inaccurate and even insulting. For example, in studies about people with mental disorders, stereotypes such as weird, bedraggled and stupid have been recorded (Lauber et al., 2006). However, in a study designed to measure the impact of a training course promoting the bio-psycho-social model of dementia, fifteen college students were asked to write down up to ten “descriptors/ideas/characteristics” that came to mind when they thought about AD (Sabat, 2011). Whilst all fairly negative attributes, the responses mainly reflected a series of possible symptoms and scenarios linked to dementia. However, with the exception of “burdensome”, they did not reflect the kind of derogatory and hostile judgements and generalisations mentioned in relation to above-mentioned study mental disorders. Nevertheless, some of the mental images of people with dementia mentioned in the previous section suggested fairly negative stereotypical beliefs about dementia.

### *Advanced dementia and severe cognitive impairments*

Some GPs have reported their awareness of a stereotype of dementia consisting just of advanced dementia (i.e. associating dementia with symptoms which typically occur later on in the disease trajectory) and being in a nursing home (Gove, 2012).

*“A typical stereotype is someone in a rest home, just eh, not doing anything, sat there, looking gormless. When you start talking about dementia, that’s the image people have. They kind of miss out the years before that.” (Gove, 2012, p.146)*

Dementia is frequently associated with a range of symptoms which people generally perceive as being unpleasant or disturbing. In most cases, they can be described in terms of deficits. People with dementia are frequently stereotyped as possessing these deficits, not only in the later stages when some are more common but throughout the course of dementia, with remaining abilities being ignored (Sabat, 2008; Swane, 1996). Eisdorfer, a psychiatrist, highlighted his perception of the discrepancy between lay stereotypes and his own observations of people with dementia.

*“We have a classic notion of what the disease is and we have a stereotype. It is (.../...) usually sort of a little old woman who is doddering around, sitting in a geriatric chair, not knowing time, place or person. This is not the way we see the disease. We have the disease in one engineer [about 62 years old] who still, after two and a half years, shoots golf in the eighties and wins tennis cups.” (Eisdorfer, cited in Ballenger, 2006, p.130)*

However, Ballenger suggests that the engineer described in the above quote is increasingly becoming the stereotype of the “dread disease” when it is not perceived in terms of senility.

### *Dangerous and disturbing behaviour*

People with mental disorders are often considered by the general public as being recognisably different, dangerous and unpredictable (Miles, 1981; Thornicroft, 2006). This is how they are regularly portrayed by the media and it is possible that this contributes towards fear and stigma. Clearly, the danger which some people with certain mental disorders represent is worrying to the general public. Moreover, when people perceive a mental disorder as resulting from a disease of the brain, they experience more fear, especially in

the case of schizophrenia. This leads to an increase of about 50% in labelling behaviour (Angermeyer and Matschinger, 2003).

As dementia is often associated with mental disorders, people with dementia are sometimes perceived as dangerous (Swane 1996), particularly if they show certain behaviours (disinhibited sexual behaviour or 'aggression') and psychiatric symptoms (e.g. delusions, hallucinations, paranoia). These behaviours and psychiatric disturbances are often grouped together as 'behavioural and psychological symptoms of dementia' (BPSD) or NeuroPsychiatric Symptoms (NPS). People with any type of dementia may react in some of these ways or experience some of these symptoms, but some are more common in some forms than in others. According to the International Psychogeriatric Association (2002), aggressive behaviour and visual hallucinations are more common in Lewy body dementia, whereas emotional instability is prominent in vascular dementia.

Studies which have measured perceived dangerousness of people with AD have reported low scores (Weiner et al., 1988; Werner and Davidson, 2004; Werner, 2005; Werner and Givon, 2008). Moreover, in Werner's 2005 study, a positive association was found between perceived dangerousness and prosocial reactions. A negative association might have been expected but this finding may be partly due to the fact that danger was operationalised as danger to self and others, perhaps resulting in people making an association with safety issues rather than aggression. Exceptionally, a fairly high score for perceived dangerousness (i.e. 41.6%) was recorded in a survey-based study of 500 lay people in Brazil (Blay and Peluso, 2010).

Dangerousness is not just about physical aggression. Cohen-Mansfield and Billig (1986) divided aggressive symptoms into those which are physically aggressive and those which are verbally aggressive. The latter might include screaming, shouting, swearing and temper outbursts. This could be very disturbing to relatives or friends of a person with dementia who has seldom if ever acted in that way. Hinshaw (2007) suggests that people may be afraid of others who seem to be out-of-control or have lost contact with reality as this may lead to behaviour which risks violating their personal space or physical integrity.

Even when people with dementia behave in a way which is perceived as being aggressive, this does not always provoke fear. Sometimes, there is a realisation that their behaviour might be an appropriate response to a difficult situation rather than a consequence of dementia. The following quotes are from a person with dementia and a GP.

*"That's such an important thing, for people to realize that lots of times, you know how we've always been labelled as being violent or reacting inappropriately, but if people were to think deeper than that, and see deeper than that, lots of times we're reacting to something, there's a trigger..." (Mitchell et al., 2006 – in Dupuis et al., 2012)*

*"They are often frightened and I think their needs are not always taken care of. If you move somebody ultimately round the ward in a hospital multiple times and confuse them and don't explain what you're doing, then it's no wonder they get frightened and potentially lash out." (Gove, 2012, p.77)*

Reports by registered nurses of violent incidents occurring in 60 municipal care homes in Sweden revealed that there was no significant difference in the frequency of violent acts towards other staff and care receivers by residents with dementia compared to residents with no dementia (Josefsson, Sonde and Wahlin, 2007). This lends support to the observa-

tion in the above quote that whilst people with dementia may sometimes react more readily with aggression, especially in care settings, they are no more violent than other people.

#### *Quality of life and capacity*

People with dementia are sometimes stereotyped as having no quality of life or capacity for pleasure, being blissfully unaware, passive and having lost their control, identity and dignity (Corner and Bond, 2005; Devlin et al., 2007; Graham et al., 2003). It has repeatedly been shown that carers perceive the quality of life of people with dementia as being lower than people with dementia perceive it themselves (e.g. Conde-Sala et al., 2009; Sands et al., 2004; Thorngrimsen et al., 2003).

Based on the findings of a German study which measured people's reported readiness to support funding or make cutbacks in expenditure for the care of people with AD, the authors suggest that some people perceive that a life with AD is "unworthy of living" and hopeless, and hence not worth saving (Schomerus, Matschinger and Angermeyer, 2006). In keeping with other conditions, perceptions of greater disease severity were linked to more reluctance to make cuts. However, in the case of AD, perceptions of it being life threatening were associated with increased willingness to accept financial cuts.

Common sense might suggest that incompetence would be a stereotype of dementia but the findings from one study suggest that this is not the case (Werner, 2006). On the other hand, people's beliefs that if they had dementia, they would not be taken seriously and would be considered "stupid and unable to do things" (Boustani et al., 2008), may reflect a stereotype that people with dementia lack capacity. Some allied healthcare professionals have also expressed concern about lay people perceiving people with dementia as being unintelligible and incapable of social interaction (Nolan et al., 2006).

Capacity should not be considered as being limited to the cognitive domain. It touches on every aspect of life and affects quality of life in many ways. Zeisel, for example, emphasises the capacity of people with dementia to experience and enjoy art. He describes how art touches and engages the brain in a more profound way than other activities and how people with dementia tend to "express what they think and feel at the moment" (Zeisel, 2010, pp.71-2).

#### **Related ethical issues**

##### *Individuality and wellbeing*

Focusing on negative, disturbing and stereotypical images of dementia and ignoring ways in which people with dementia resemble other members of society may contribute towards an unrealistic fear of dementia and interfere with authentic communication with people with dementia. This may contribute towards stigmatization and be damaging to existing and potential relationships between people with dementia and others.

As the likelihood of developing dementia increases with age, everyone is to some extent at risk of having dementia one day. Consequently, the way that dementia is perceived has greater personal relevance than some other conditions as many people are aware that they might one day be in the position of the person they are observing. This could be summed up by the idiomatic expression "There but for the grace of God go I" (i.e. a personal reflection that someone else's misfortune could be one's own if it weren't for some kind of divine blessing).

The focus on generalisations about people with dementia and the lack of attention to the personal needs and preferences of people with dementia may lead to the individuality and uniqueness of each person being overlooked. At the same time, there is a risk in trying to challenge stereotypes about people with dementia having no quality of life or overlooking individual experience, depressed feelings and actual depression (i.e. of failing to see people with dementia for whom life really does lack quality). Acknowledging individual experience and taking measures to prevent and if necessary to treat depression are also practical ways to address stereotypes and this involves looking at the way that people with dementia are treated, listening to what is important to them and providing good quality and appropriate care.

The fear and disgust sometimes associated with the images that people have of dementia, may lead to a distancing from the disturbing images and hence from the person. If the various characteristics perceived are considered as belonging to a person with dementia (i.e. s/he is passive, dirty and incontinent) and not the result of the physical, emotional and care environment in which the person finds him/herself (i.e. s/he is not being provided with social and cognitive stimulation or being provided with appropriate assistance with toileting and hygiene), the person's physical and emotional wellbeing may be threatened.

#### *Dignity and respect*

Negative perceptions and associated personal judgements are likely to be reflected back to people with dementia. This may affect their self-esteem and sense of dignity. Often, the images we have of dementia reflect the level of dignity and respect, as well as the level of care and consideration, accorded to people with dementia by other members of society. For example, the practice of having "toilet rounds" in some nursing homes (Alzheimer Europe, 2012) or inadequate staffing levels may result in many people with dementia sitting in soiled clothing or continence pads. Similarly, the limited amount of time dedicated to one-to-one contact between staff and people with dementia or to organised activities during the day means that many people with dementia are under-stimulated, which may result in premature loss of capacity and apathy. Consequently, the images that people have of dementia are often biased towards negative or feared symptoms, which may be based on stereotypes but may also sometimes be based on inferior standards of care tolerated by society.

#### *Fear*

Stereotypes of advanced dementia, dangerousness and people with dementia having no quality of life may contribute towards fear, which has implications for stigma, social distancing, and inappropriate and poor quality of care. Often, stereotypes of people with dementia being aggressive or dangerous seem to imply that these characteristics derive from the condition itself. There may be a tendency to overlook external factors which might be contributing towards or which might help explain the observed behaviour. Adopting a bio-psycho-social perspective on dementia might contribute towards a more understanding and comprehensive overview of the situation, avoiding the attribution of blame and identifying contributing environmental factors and the person's possible needs.

#### *Discrimination and survival*

Perceptions of people with dementia, especially severe dementia, having no quality of life could in some cases be stereotypes and in others, individual assessments of the quality of

life of a person with dementia. Stereotypes of a lack of quality of life could have serious implications for end-of-life decision making by influencing life and death decision-making in the absence of knowledge about the wishes and feelings of the person with dementia. There are therefore ethical implications linked to beneficence, non-maleficence, wellbeing, dignity and personhood.

Physician-assisted suicide is illegal in most EU member states but allowing a person to die through withholding food or liquid, or not attempting resuscitation, is often a clinical decision for which healthcare professionals, in the absence of an advance directive, consult relatives and carers. Presumed quality of life is a factor which frequently contributes towards decision making. Stereotypes of people with dementia being unable to do anything for themselves and totally dependent on others may also contribute to such decisions. Williams et al. (2007) highlight two studies which indicate that 62% of the general public in the Netherlands and 48% in Finland were in favour of active voluntary euthanasia for people with dementia. In their own survey involving 725 members of the general public in the UK, percentages of people who would be in favour of their partner with mild, moderate or severe dementia being allowed to die (i.e. passive euthanasia) were 61.1%, 64.3% and 68.9% respectively. Percentages were slightly higher for the same decision with regard to themselves. There were cultural/ethnic differences in that the White respondents were significantly less in favour of life-sustaining treatments than their Black, Asian and other ethnic counterparts. Perceptions of quality of life or capacity in relation to dementia were not measured and conclusions cannot therefore be drawn but it would be helpful to determine whether there is a relationship between the two.

Williams et al. (2007) suggest the usefulness of measuring the attitudes of people with dementia about this issue. This might be ethically difficult, however, as involvement in such a study or merely inviting people with dementia to participate may be emotionally disturbing and result in a decision which would not otherwise have been made, especially if they considered dementia a stigma and felt that people with dementia were not valued and were perceived as a burden.



### ***Ability/willingness to reciprocate***

Perceived lack of reciprocity can be detected in the images that people have of people with dementia (i.e. being passive, immobile, withdrawn and unresponsive) and in terms used to describe or refer to people with dementia as being absent or lacking a mind. Communication with people with dementia is sometimes described in terms which emphasise it being one-sided, unrewarding, awkward and even embarrassing. Failure to give something back in the context of relationships has also been noted, sometimes resulting in people no longer fulfilling a role or the nature of roles changing. Giving something back can even take the form of a smile or a look in the eyes which shows that the person with dementia recognises the people around him/her. Loss of the ability to recognise familiar faces is frequently described by carers as being difficult to handle. However, Haaning (2000) found that caregiving in Danish couples, where one spouse has dementia, can be an enriching experience for the caring spouse.

The findings from a qualitative studying involving 100 dyads of people with AD and their carers suggest that give and take in care relationships is somewhat richer and less straight-

forward than it is often portrayed. Graham and Bassett (2006) explain that people with dementia are often perceived as passive, unresponsive recipients of care and carers as active providers, and that research into caregiving often focuses on carers (e.g. on “care-giver burden”, stress, their coping strategies and their support needs). Drawing on the literature, they point out that caregiving is often perceived as a unidirectional relationship of care for a care recipient who lacks agency and power and is not an equal partner in the relationship. Based on their interviews and ethnographic notes, they highlight a range of responses from people with dementia in receipt of care such as acceptance/resistance, cooperation/conflict, togetherness/detachment which suggest that people with dementia do not passively experience dementia or care. A key finding from this study is that carers often have normative expectations of reciprocity based on “an old self” (i.e. the way the person with dementia reciprocated before s/he had dementia) and that such expectations result in them failing to perceive subtle ways in which the person with dementia is currently reciprocating and engaging with his/her environment. Behaviours and reactions, which appear to be incongruent with the person prior to dementia, are interpreted as being a consequence of the disease and the person with dementia is not recognised. This is an interesting perception of the care dyad in which the carer is the one who is perceived as failing to recognise the person with dementia and not vice versa, although the latter is often also the case.

People with dementia may be perceived as eventually failing to contribute towards society through meaningful participation in social, cultural, civil, political and religious events, but also through the production or provision of things that are valued in society, including the fulfilment of social roles. This reflects perceived lack of reciprocity at the level of society. Some GPs, for example, were concerned that people with dementia are perceived by society as taking more than they are able to give and of the consequences of such perceptions.

*“But you know if you take the generality of what one senses is the general mores of this country, I think people value production. They value people who produce things or people who make you feel good, people who serve you. And those are kinds of things that the elderly in general and the demented in particular don’t do.” (Gove, 2012, p. 172)*

*“It’s like a group of people waiting to die, who no longer contribute. I mean we all expect older people when they are retired not to be working but they still give a lot back in other aspects of life but I think that starts to...., even that goes you know, in people with dementia.” (Gove, 2012, p.292)*

### **Related ethical issues**

According to the evolutionary theory of stigma of Kurzban and Leary (2001), which focuses on the process of social exclusion, reciprocity is important for social cohesion but failure to reciprocate tends to be tolerated if the people concerned are unable rather than unwilling to do so (e.g. due to disability or advanced dementia). However, perceived lack of reciprocity on the part of people with dementia may contribute towards dementia being perceived as a stigma (Gove, 2012) and hence to the possibility of people with dementia being stigmatized or experiencing self-stigma and this has ethical implications as mentioned earlier.

Some of the ways that people with dementia are perceived as failing to reciprocate cannot be attributed solely to the individuals themselves. For example, failure to reciprocate

in the context of communication and social interaction may be dependent on a whole range of factors such as the context and atmosphere of care, the availability of opportunities and activities, whether people spend sufficient time with people with dementia and whether they have the knowledge and skills to interact or facilitate interaction with them. If people with dementia would benefit from AD drugs but are not receiving them, then their potential capacity to reciprocate is being unfairly restricted. Finally, the restriction of freedom experienced by many people with dementia in residential care, linked to freedom to express their individuality, values and preferences (see Alzheimer Europe, 2012), may result in boredom, depression and apathy which are not conducive to reciprocity.

Failure to reciprocate by acknowledging recognition of other people has been associated with social distancing and reduced caring activities for people with dementia (Liu et al., 2008 in Werner et al., 2011). Vernooij-Dassen et al. (2011) describe reciprocity as a basic human need which is often unmet in frail, older people. This would also apply to people with dementia. They emphasise the importance of recognising that need and providing opportunities for reciprocation within the context of care. People without dementia therefore have a moral duty to facilitate reciprocity in people with dementia.

Graham and Bassett (2006) suggest that in failing to perceive subtle signs of reciprocity on the part of the person with dementia, carers may take over too much. In addition, they may unwittingly contribute toward the person with dementia losing their remaining capacities, thus reducing the possibility for agency and self-confidence, including the ability to reciprocate. The message from Graham and Bassett highlights the need to be more flexible in interpreting the behaviour of people with dementia and to avoid “writing them off” as unwilling or unable to reciprocate. Carers also have a responsibility to look for signs of give and take and not to position the person with dementia through normative expectations which are perhaps no longer meaningful for the latter.



### ***Vulnerability, dependency and potential burden***

#### *Vulnerability*

People with dementia are often perceived as vulnerable (i.e. relatively or absolutely incapable of protecting their own interests). They are also often stereotyped as vulnerable in the sense that a generalisation is made that all people with dementia are vulnerable (Bartlam et al., 2010). Perceptions of vulnerability may be associated with age, cognitive impairment, being dependent on others for care and/or being a resident in a long-term care institution. Additional factors may co-exist based on being a member of an ethnic minority group, gender, physical disability, sexual orientation and living situation (e.g. being homeless, a prisoner or nomadic). Vulnerability may also be contextual and influenced by dynamic processes which are not permanent (e.g. based on a particular situation or context). It is likely that perceptions of people being vulnerable are accompanied by beliefs about the kind of care and support they may need. In the context of dementia, this creates a link to the concept of dependency and depending on how this is perceived, to that of burden.

Perceptions and the portrayal of people with dementia as being vulnerable have also been associated with the kind of care, support and treatment they are offered. Due to the tendency to focus on the advanced stage, dementia is often associated with increased dependency and the need to move into residential care. Perceptions of care homes being

places where discrimination and abuse occur become associated with perceptions of what it means to have dementia. In many care homes, people with dementia are persistently over-prescribed anti-psychotic medication despite the recognised risk of such drugs for people with dementia and the fact that they have only shown limited efficacy for the treatment of BPSD (Banerjee, 2009). This can be considered as structural discrimination as the practice often primarily reflects the policy of homes rather than individuals and as such practices would not be considered acceptable for other groups of people (e.g. infants or children). Fortunately, this does not happen in all homes and a gradual change in perceptions is evident from recent calls to reduce inappropriate drug prescription and the restraint of people with dementia (Alzheimer Europe, 2012; Banerjee, 2009).

Nevertheless, a survey, involving carers, people with dementia and staff in care homes combined with a "YouGov" poll of 2,060 adults into perceptions of care homes, revealed that the principal concern of 53% of UK adults in connection with their relative moving into a care home was that s/he would be abused. In the "YouGov" public poll, 70% of adults reported being fairly or very scared about the prospect of one day moving into a care home (Alzheimer's Society, 2013). Some healthcare professionals have also reported concerns about people with dementia being subjected to healthcare discrimination such as unequal access to treatment and surgery, being denied access to certain daycare centres and nursing homes and receiving sub-optimal, inadequate and inappropriate care and support (Cahill et al., 2008; Gove, 2012).

Although forms of structural discrimination persist, it is heartening to note that such practices are increasingly being challenged and that there is an awareness that the vulnerability of people with dementia is heightened in some situations where they are dependent on others.

#### *Dependency*

Dependency is generally seen in a negative light. Many people find it difficult to accept that they are dependent on others and may have internalised common perceptions of dependency as a burden to loved ones and to society. In the context of an observational study in a care home, Small et al. (1998) found that residents with dementia resisted being positioned as dependent by care staff and cooperated more when treated as independent. Sometimes, perceptions of dementia caregiving reflect an understanding of dependency as an opportunity to give something back for care or love received earlier or in terms of solidarity, interdependence and mutual support (Alzheimer Europe, 2001; Hanning, 2000).

*"It's nice to be able to do for my father what he did for me as a child and as an adult."  
[Danish carer] (Alzheimer Europe, 2001, p.27)*

*"I understand that we all need someone sometimes. I am giving my mother something she gave me before i.e. love and care." [Spanish carer] (Alzheimer Europe, 2001, p.27)*

Graham and Bassett (2006) describe another perspective which is one based on cooperative relationships that typically involve doing things for each other, picking up when the other cannot, prompting without judgement and doing things for the other person based on the desire to do so rather than a sense of duty or obligation. One man who was interviewed stated in relation to helping his wife:



*"I'm taking care of things that I WANT to do, and I don't mind doing it, but I don't HAVE to take care of Helen (Graham and Bassett, 2006, p.339)*

The perception or portrayal of dementia as a condition leading to dependency is reflected in national, European and international reports and documents which recognise that the cognitive and physical impairments associated with dementia interfere with independent living and necessitate organised support, care and treatment. Recognition of the dependency of people with dementia on individuals and the state can be interpreted and portrayed in different ways, and as something that is positive, negative or neutral.

### *Burden*

The World Health Organisation describes mental disorders as a burden, stating,

*"The burden of mental disorders is great. 1. Mental disorders are prevalent in all societies. They create a substantial personal burden for affected individuals and their families, and they produce significant economic and social hardships that affect society as a whole." (WHO/WONCA, 2008, p.3)*

The term "the global burden of disease" has also been used to describe the population impact of various conditions, such as dementia, on mortality and disability (Alzheimer's Disease International, 2012), which creates a clear link between disability and burden. The term "burden" is also widely used with specific reference to the impact of care on relatives and partners of people with dementia, as well as at the level of society in relation to the cost of care and a decreasing proportion of potential future carers, both formal and informal. The Prince of Wales drew attention to the "emotional, social and economic burden we will all face if (dementia) is left unchecked" (Alzheimer Europe, 2009, p. 46). In this case, it is dementia, the condition itself, that is considered a burden and the phrase "we will all face" could be interpreted as uniting people with and without dementia in addressing dementia rather than singling out people with dementia as the problem, or even the burden.

The perception of dementia as a burden is often either directly stated or implied in references to the scarcity of funds for healthcare and the subsequent strain on the economy (George, 2010). As demonstrated in the study by Schomerus et al. (2006) on decisions related to public funding of various health conditions, the notion of expenditure on AD was relatively well supported by the general public in Germany. However, reports of resentment linked to the cost of care for older people are sometimes expressed. The following quotes demonstrate older people and people with dementia are sometimes perceived as a financial threat and burden.

*"There's going to be less and less patience with the fact that we're going to have a massive rise in over 85-year olds and hence a massive rise in dementias and hence a smaller number of people who are paying the pension and care for all these older people. You could almost imagine, God help us, that it could be like George Orwell saying that you need euthanasia by a certain age." (Gove, 2012, p.244)*

*"I don't think it's right that money is taken away from children and the like... to treat the elderly and the demented." (Corner and Bond, 2004, pp. 148)*

Swane (1996) describes a "burden paradigm" in which people with dementia are perceived solely as a strain on the family and their "deviant behaviour" as a specific strain on profes-

sionals in institutions. Research into the care of people with dementia and reports about the impact and experience of care heavily reflect this burden paradigm (Swane, 1996).

In a large-scale survey involving 618 carers in six countries, most carers described their role as isolating (62%), depressing (69%), exhausting (89%) and life changing (94%), but almost one third described their role as rewarding and/or fulfilling (27% and 30% respectively). The researchers described this as surprising and heartening, and point out that this was perhaps even an underestimate based on people's tendency to focus on the difficulties they encounter (Bond et al., 2005). Another large-scale, Internet-based survey involving 949 members of the general public, 500 physicians, 250 carers and 50 "payors" from five countries reported:

*"All respondents recognised that AD has a devastating impact on the lives of the affected person and his or her family. Caregivers experience a physical burden as well as emotional stress, social isolation and in some cases financial loss...." (Jones et al., 2010).*

The researchers acknowledged that a minority of carers reported a positive aspect to their situation but emphasised that the study highlights the burden of caregiving and serves as a challenge to society and the health care community to provide effective solutions so that the positive aspects of caring can be enhanced. In this way, they report carers' perceptions of the impact of dementia as a potential burden but also as a positive experience for some people.

### **Related ethical issues**

#### *Balancing protection and respect for autonomy*

The perception of people with dementia as a vulnerable group rather than as individuals with varying levels, risks and types of vulnerability is problematic. A group-based approach to vulnerability detracts somewhat from the perception of the potential vulnerability of all human beings (as being capable of suffering) as well as of the increased vulnerability of individuals based on reasons which are not immediately evident. It increases the risk of perceiving vulnerable people as "the problem" and to overlooking similarities and differences amongst people with dementia and between them and other people. Many groups require the same type of protection, some people belong to more than one group and some members of a group may need additional protection with regard to certain issues but not others (DuBois, 2008). Considering people with dementia, as a whole, as vulnerable (or dependent) amounts to stereotyping. This may also involve attaching additional attributes to people with dementia such as weak, needy, powerless and lacking capacity etc. which might contribute towards their stigmatization. Such generalizations might result in their over-protection, threaten their right to exercise autonomy and in some cases to the premature loss of capacities. A generalised perception of vulnerability or dependency could thus reinforce paternalism and reduce possibilities for positive risk taking, which is a part of everyday life. There may also be power issues involved in that people with dementia who are perceived and thus positioned as vulnerable may find it difficult to defend their right to take certain risks (e.g. to walk about freely, get out of bed or go out for a walk), especially if part of the perceived vulnerability consists of being unable to assess risk. Within institutional care settings, positioning all people with dementia as vulnerable (combined with litigation fears of staff linked to possible accidents) may result in unnecessary restrictions of freedom for some residents.

An individualised/non-group based approach to vulnerability and dependency is required, involving the assessment of specific vulnerabilities, support requirements and possible risks. By being more precise about what kind of vulnerability is an issue in a particular situation and not considering people with dementia in a blanket fashion as vulnerable or dependent may contribute towards such perceptions being helpful to people with dementia and not working against them.

#### *Give and take/solidarity*

In older people, especially those who have dementia, dependency is often portrayed in a negative light (e.g. as a problem and a potential cost) and the many ways in which they have already contributed towards society may be overlooked. The ways in which they could still play an active role in society may be limited by a lack of understanding about dementia and/or a failure to provide people the support they need.

Hockey and James (1993) point out that dependency can occur at any stage in the life continuum by people who are ill or well (e.g. in varying degrees through infancy, accidents, illnesses and old age etc.). People are all dependent on each other in numerous ways throughout the whole course of their lives (e.g. for food, clothing and services but also for more emotional, social and psychological needs). Agich (2003) suggests that as dependency is not limited to old age and frailty, it should not be expressed as a consequence of such. Dependency may be experienced by some but not all elderly people and by some but not all people with dementia and in varying degrees.

Dependency can be reframed in a more positive light as interdependence involving mutual responsibility and the sharing of a common set of principles reflecting solidarity. The principle of solidarity is closely linked to that of justice/equity as it covers the issue of cooperation between people. It recognises that some groups of people are potentially vulnerable and may need support. At different stages of their lives people are more or less likely to be in a position to give or receive support and this is not limited solely to age. Sometimes, support is portrayed in fairly neutral terms which reflects solidarity and citizens' rights to the services and support they need but sometimes, especially in times of economic hardship, it is portrayed in terms which suggest burden or a crisis.

#### *Self-esteem and scapegoating*

The polarisation of the concepts of independency and dependency serves as a means to demarcate and position certain people with dementia in relation to the rest of society and may lead to their loss of power and devaluation. The use of the term "burden" and the measurement of it by researchers may reinforce perceptions of people with dementia and the experience of care as a burden, particularly when combined with alarmist and sensationalist reporting in the media of increasing numbers of people with dementia and the cost of care. Sometimes the term burden is used in studies to categorise or report findings even though the participants did not use that specific term and might not feel that caregiving or people with dementia are a burden. The feeling that one has become or may become a burden is likely to be damaging to a person's self-esteem and may contribute towards the fear of dementia and even affect advance decision making about end-of-life treatment options.

If considered a burden to society, people with dementia may become scapegoats in that they are perceived as being responsible for a worrying economic situation and using up

valuable resources which could be used in other domains. In this sense, it is as if they are blamed for having dementia and there is a presumption that they are less deserving of the expenditure, which is a reflection of their perceived lack of value<sup>3</sup>. Governments decide which aspects to emphasise and how to organise expenditure. It is a choice to highlight the cost of dementia care and to make limited reference to other costs such as those linked, for example, to military defence, the maintenance of roads or the entertainment of dignitaries.

## The portrayal of dementia in the media

We are exposed to messages and information about dementia in our everyday lives through the media (newspapers, television, radio, magazines and the Internet). This may be in written, auditory or visual form. Information about dementia may be communicated directly or in a peripheral manner and we might attend to it actively (e.g. by watching a documentary or reading an article) or passively (e.g. a secondary character in our favorite soap opera happens to have dementia or there is a discussion on the radio which we hear without paying much attention to it). Flicking through a magazine, we might come across an advert for dementia drugs or donations for research, or a story written by a carer or a person with dementia which might attract our attention. In this section, we examine how dementia is portrayed in the media with particular reference to the use of frames and the issue of accuracy as well as possible sensationalism.

### *The use of frames in the media*

The media has been described as a powerful tool to communicate information about health issues, both creating awareness and influencing perceptions, beliefs and attitudes (Doyle et al., 2012). However, the same tool has been reported as portraying negative images of dementia, perpetuating stereotypes about ageing, and inciting fear and stigma (Clarke, 2006; Kirkman, 2006).

Within the context of the social constructivist approach mentioned earlier, Van Gorp, Ver-cruysse and Van den Bulck (2012) suggest that the media uses “frames” to offer a certain perspective to audiences and the general public. Frames are described as socially shared “organising principles” which offer

*“a perspective, a view of reality, but at the expense of other possible angles, which disappear from the field of vision (Van Gorp et al., 2012, p.389)*

As frames form part of the culture in which they are used, they are common to both senders and receivers and as such, the process of framing can easily go unnoticed. The frames draw on the values, metaphors and images which are part of the taken-for-granted socially constructed knowledge about how the world functions and which enable people to process complex raw experience into more comprehensible patterns which are thus more manageable (Lakoff, 2004). They are often too obvious to be challenged.

Frames lead to different ways of interpreting “reality” and could also be used in the context of various forms of strategic communication. Van Gorp et al. (2012) identified six frames and for each proposed a counter-frame, not aimed at replacing the frame but rather at offering an alternative perspective which is more nuanced but also credible and compre-

<sup>3</sup> See Murphy (1987) and Ryan (1976) for more about scapegoating and blaming the victim

hensive to the general public. For example, a common frame is that of “the invader”, a kind of personification of dementia (other alternatives being a monster or a thief), often accompanied by fighting or defensive terminology. Other frames included “faith in science” (focusing on scientific/biological explanations), reversed roles (focusing on a “return to childhood”) and “no reciprocation” (focusing on lack of reciprocity and the loss of a shared past). The two most dominant frames, according to Van Gorp et al. (2012) were “dualism” (i.e. the separation between mind and body and the loss of the mind) and the fear of death (focusing on death, degeneration and the start of an ordeal). The frames and counter-frames are as follows:

| Frame                    | Counter frame                    |
|--------------------------|----------------------------------|
| Dualism of mind and body | Unity of body and mind           |
| The invader              | The strange travelling companion |
| Faith in science         | Natural ageing                   |
| The fear of death        | Carpe diem                       |
| Reversed roles           | Each in turn                     |
| No reciprocation         | The good mother                  |

Source: Van Gorp and Vercruyse, 2011

The frames were identified through an extensive search of a diverse range of materials and the qualitative analysis of emerging frames by means of open coding. Some of the counter frames, on the other hand, were actively sought using the same “framing devices” for the frames and therefore had a strength of conviction linked to the dominant frame. Others were new and did not draw attention to the dominant frame. Van Gorp and Vercruyse (2011) point out that everyone uses the dominant frames whereas the counter-frames were used by people with dementia, carers and their friends.

### ***Accuracy and sensationalism in news reporting and soap operas***

Drawing on studies into the way that dementia is portrayed in the media, Van Gorp and Vercruyse (2012) highlight three issues:

1. There is a focus on the terminal stage of dementia which becomes representative of the whole trajectory of dementia,
2. People speak on behalf of people with dementia who rarely have the opportunity to speak for themselves and
3. The burden of dementia on the family is emphasised.

Representations of dementia in the media and from official sources may sometimes be confusing and conflicting. Jolley and Benbow (2000) accuse the media of presenting negative discourses and fuelling stereotypes. Moreover, messages from the media can be incorrect and deliberately misleading in an attempt to sensationalize a news event and attract readership.

Nevertheless Doyle et al. (2012) suggest that this may be changing for the better. They analysed the quality of reporting on dementia (as well as on seven other categories) between 2000/2001 and 2006/2007 in the Australian media. Despite some deterioration regarding the use of medical terminology and in focusing on the disease rather than the person, large improvements were reported in that sensationalist reporting and the use of outdated, inappropriate or negative terms were much less, and there was much more

provision of information about help services. Positive representations of dementia have also been noted by Kessler and Schender (2012) in a study of German news magazines (in Zeilig, 2013).

In the United Kingdom and Ireland, there have been mixed reactions but mainly positive ones to the portrayal of dementia in soap operas (Alzheimer's Society, 2011; Nolan et al., 2006). Commenting on the storyline surrounding the screen character Mike Baldwin in "Coronation Street", the Alzheimer's Society (2011) commented that it provided "an opportunity to raise awareness about dementia at a time when it was not high on the political agenda". The performance of Johnny Briggs as Mike Baldwin was lauded for its accuracy but the storyline criticised for his rapid deterioration and death. Another character in "Coronation Street", Eileen Grimshaw played the role of a woman with early onset dementia. In the American television series "Grey's Anatomy", the mother of the character Meredith Grey develops AD and Meredith is concerned that she might develop it too. Stevenson (2013) highlights the way that such portrayals of dementia, as well as those where dementia is covered in a more peripheral way rather than through a main character, bring awareness to a widespread audience, highlighting issues such as early-onset dementia, heritability, relationships, combining work with caring and mistreatment.

In a long-running soap opera in the Czech Republic, one of the main characters (Mr Kral) is portrayed as having advanced dementia. The series accompanies Mr Kral, a shopkeeper and the life and soul of a small family business called "The Kingdom of Toys", right from the first perceived symptoms and his fear of diagnosis through to more advanced symptoms and apparent changes in character and behaviour. This seems to have been done in a sensitive way and provides viewers with a possibility to empathise with the character over time without recourse to fear tactics and sensationalism (Kasparkova, 2013).

### **Related ethical issues**

The use of frames has ethical implications as they can be deliberately used to increase the likelihood of dementia being perceived in a particular way. The impact that this might have on people with dementia depends on the aspects or possible ways of perceiving dementia that the frame is designed to convey. The aim of a particular frame may, for example, be to create fear, emphasise the impact of dementia on carers or on society, justify the need for research or the value of medication or appropriate care, or simply to create a sensational headline. The particular frame used is presumably considered the most effective way to achieve such aims. The deliberate use of certain frames, or combinations of frames, to convey a biased image of dementia, focusing on certain aspects at the expense of others, is a form of persuasive communication which is not far removed from propaganda which also aims to influence or change public opinion (see section on strategic communication). Van Gorp et al. (2012) have promoted a more critical approach to making sense of dementia as they have drawn attention to the way that the portrayal of dementia is packaged and presented to the general public. They have also emphasised the importance of making greater and more resolute use of counter-frames without minimising the seriousness of dementia or denying the last phase of dementia.

The identification of both frames and counter-frames might be seen to imply that there are certain ways of portraying dementia which are good and others which are bad. However, the frames have merely been identified as providing a narrow perspective of dementia which does not reflect the complexity of the condition and which focuses in some cases

on aspects of dementia which people find disturbing. The counter-frames were devised to provide a more balanced, nuanced view of the aspect of dementia being presented in the frame but are dependent on the perceptions of a smaller group of people and the way that they perceive dementia. Some might be challenged based on a different interpretation. The concept of natural ageing in relation to dementia, for example, is a highly controversial topic and considered by some people as being inaccurate and interfering with timely diagnosis. Clearly, both frames and counter-frames are open to individual interpretation and may be rejected, missed or challenged. Both will develop and change over time as the taken-for-granted reality of dementia also develops.

With reference to British soap operas, Hargrave and Gatfield (2002) suggest that they are a useful means to present sensitive issues in an engaging way, allowing viewers to learn without being lectured to, but that due to time constraints and the need to avoid boring the audience, issues are sometimes only explored at a superficial and dramatically engaging level. In their analysis of audience attitudes to soap operas, they found that only 54% of viewers (2,100 respondents) expected information about social issues to be factually correct. They conclude that audiences want soap operas to be realistic rather than real, providing “a window into other people’s lives”. Nevertheless, the study also suggested that viewers often identified with certain characters, related to certain topics and frequently discussed the societal issues addressed afterwards with other people. Consequently, soap operas should ideally portray the medical aspects of dementia as accurately as possible and realistically reflect the social reality of dementia in today’s society.

The reported responses of some people to portrayals of dementia in soap operas, particularly those made by carers and people with dementia, suggest the importance of their feeling understood and encouraged by the potential of such soap operas to contribute towards a better understanding of dementia (Hargrave and Gatfield, 2002), which has implications for attitudes towards people with dementia. On the other hand, with reference to the rapid decline of the screen character, Mike Baldwin (mentioned above), his decline was atypical and based on complications such as a stroke and pneumonia. This may have contributed towards unrealistic perceptions about the timescale of dementia amongst many viewers (Elliott, 2006). This may further contribute towards fears about dementia and about receiving a diagnosis. Consequently, soap opera producers perhaps have a moral obligation to accurately and sensitively portray dementia, even if this is not a high priority for viewers, due to the impact that such portrayals can have on people’s emotional wellbeing.

## The portrayal of dementia in films

Films represent another medium through which to portray dementia and which may influence people’s perceptions of dementia and people with dementia. In this section, we look at the kinds of images and information about dementia, as well as emotions, conveyed through films, and consider how this might be received and interpreted by viewers.

### *The overall approach*

As with soap operas, film producers do not merely set out to provide an accurate description of dementia. They have an interest in obtaining a certain impact, in providing entertainment, suspense and dramatic effect, allow themselves a certain artistic license, working within the framework of various film genres and positioning potential spectators.

Everything that the spectator sees or hears (and even the absence of image and sound in some cases) is motivated, leading the spectator to make assumptions, to draw on common frames, to have expectations or to make interpretations. Spectators make sense of films using the same cognitive processes for “perceiving, conceiving, analogizing, deducing, explaining and deliberating” as they do in the real world (Oakley, undated, p.26). However, various techniques may be used to create a mood or arouse emotions and to provide the spectator with a window on the world which is actually a picture of a certain “reality”.

There are different levels of meaning in films based on the referential content (basically what happens, like a synopsis), the explicit content (conveyed directly and openly through the mouths and actions of the characters) and the implicit content (which is less obvious but may, for example, be detectable by following through the development, change and growth of characters throughout the film) (Jacobs, 2013). In addition, there is a symptomatic content which is often ideological in that it represents the person opinions of the filmmaker and may, consciously or otherwise, reflect contemporary concerns. In the context of dementia, examples of symptomatic content might include how people with dementia are treated within society, how dementia affects relationships, the role of informal carers versus the state in the care of people with dementia or the perceived place of people with dementia in society. Such issues may be a reflection of the historical period, the cultural context and the filmmakers own experience as s/he is also involved in the social construction of meanings around dementia within a particular social and historical context.

In most films about dementia, the person with dementia is not the central character. S/he tends to be the catalyst in that s/he triggers events and consequences for other people, and the perspective of carers is often prominent (Scheidt et al., 2013). According to Scheidt et al. (2013) even when the focus seems to be on the person with dementia, such as in the films “Iris” and “Away from Her”, the dominant point of view tends to be that of the spouse. The film “The Iron Lady” is deemed an exception. The absence of the perspective of the person with dementia is open to interpretation. It could, for example, been interpreted as an objectification of the person with dementia, a preoccupation with the impact of dementia on carers (perhaps even suggesting that it is harder for carers) but perhaps also a portrayal of the difficulties understanding and communicating with people with dementia or in some cases of the stereotype of blissful lack of awareness.

### ***The clinical picture of dementia***

In the context of cinema films, the explicit portrayal of the clinical picture of dementia has been found to be fairly accurate but with an emphasis in some films on behavioural disturbances and aggressiveness and some films suggesting sudden periods of full insight (Segers, 2007). In these films (24 released between 1970 and 2004), the people with dementia depicted were mostly in their seventies and eighties and highly educated. A more recent analysis of the portrayal of dementia in 23 films (released between 2000 and 2012) also revealed a fairly accurate representation of dementia but with an emphasis on cognitive symptoms (mainly memory, disorientation and word finding), fluctuations of consciousness and disengaged behaviour (apathy, being in one’s own world and lack of facial expression) (Gerritsen, Kuin and Nijboer, 2013). The authors of this recent study highlight the inconsistencies in some films, especially with regard to the portrayal of memory, insight and recognition. For example, they described how in the film “The Notebook” the main character is portrayed as having moments of lucidity and intense contact with her



husband after long periods of not recognising him. In another film, "The Iron Lady", Gerritsen et al., (2013) highlight the problematic portrayal of the main character (Margaret Thatcher) as regularly and promptly switching back to "reality" when interrupted during hallucinations.

### ***The emotional impact of films about dementia***

Whereas authors of books can describe in detail the emotional experience of the various characters, the portrayal of emotions in films may be achieved by a variety of means such as through image, movement, background sound, lighting, symbolism and the angle, depth or perspective of the shot. It is not always necessary or appropriate to explicitly state the emotion supposedly being experienced. In the case of dementia, doing so may be further hampered by the portrayal of the character as having communication difficulties.

In addition to portraying the emotional experiences of certain film characters, films are also invitations for viewers to feel emotions. According to Smith (2004), the invitation to feel can be accepted in a number of ways or recognised but rejected, and some people may not have the prerequisite skills to read the emotion cues offered. Consequently, the film makers cannot guarantee a certain emotional reaction. Differences in emotional responses may be dependent on people's individual experiences which have shaped their emotion networks and in the case of dementia, their familiarity with dementia and whether they have already been emotionally affected by it in a positive or negative way. This is in keeping with Gerritsen et al. (2013) who report that some films about dementia have been judged by some as creating a distance to the main character with dementia and being about loss and hopelessness, and by others as giving rise to feelings of empathy, hope and acceptance. Nevertheless, there is limited information about the emotions which films about dementia arouse and what those emotions reveal about the way that dementia is perceived as a possible future prospect in relation to oneself.

Commenting on the films *Iris*, *The Notebook* and *Do you remember love?* Basting (2009) suggests that they all tell a story of tragic loss and questions whether dementia is only a tragedy and if not, what has been left out of these stories. This highlights the importance not only of the emotional or other content of films but on which aspects of dementia are not portrayed. She cites a comment from another critic of the film *Away from her*, which was that the film was perhaps "less a drama about Alzheimer's disease than a cinematic poem of love and loss" (Basting, 2009, p. 49). This raises the question as to whether every film in which the central character has dementia must necessarily be about dementia. There is almost a presumption that it must be as if that is all that the person with dementia could possibly represent.

### ***Expression of self and of personhood***

Neither loss of self nor loss of personhood was one of the 54 categories identified in the content analysis of 23 films by Gerritsen et al. (2013) as they were looking for examples of the portrayal of clinical features of dementia. However, they point out that in just over half of the films, people with dementia were portrayed as having something to offer, both socially and emotionally, even in the advanced stage of dementia. This implies a portrayal of people with dementia as active agents, able to reciprocate and interact with others either verbally or non-verbally.

In the novel "Out of Mind", Bernlef (1988) suggests that without language, there is no longer a story to tell or a person to hold on to (recounted by Swinnen, 2012). However, personhood and self are also depicted through action in the form of maintaining social roles. In the Swedish film "Wellkåmm to Verona", the main character is described by Swinnen (2012) as being "an undeniable subject" based on the roles he is portrayed as possessing, namely a skillful seducer, a convincing actor, a canny director and a persistent lover. This is in stark contrast to the withdrawn behaviour (e.g. being in one's own world, lack of initiative, passiveness, apathy and lack of facial expression) and communication difficulties portrayed in the films analysed by Gerritsen et al. (2013). The two types of portrayal may in effect provide a balanced portrayal of dementia.

Drawing on Post's (1995) description of hypercognitivism, Swinnen reflects on the possibility that film producers contribute towards maintaining the stigma of dementia and to people's perception of a dissolution of the self through their emphasis on cognitive difficulties (such as language and memory).

With reference to a documentary film ("Mum"), Swinnen (2012) suggests that the portrayal of caring for a person with dementia invites viewers to perceive the continued personhood of the mother who has dementia as well as the importance of relationships in connection with caring. This provides a contrast to portrayals of dementia which focus on loss of personhood and the breakdown of relationships.

### ***Relationships***

Several films in which one of the principal actors has dementia portray the impact of dementia on relationships. In most cases, these films are melodramatic love stories in which the couples are portrayed as victims of dementia which is eventually the cause of their separation (Wulff, 2008). In some films this separation is both physical (in terms of resulting in a geographical distance) and emotional (resulting in a loss of recognition of the partner, of their collective memories and of intimacy and affection). Swinnen (2012) suggests that the film makers introduce the idea of a "love miracle" whereby the caring partner enables the person with dementia to remember the affection they had/have for each other. Gerritsen et al. (2013) describe this as the portrayal of a false hope that many carers have of their partner with dementia remembering their relationship. Alongside, the total breakdown or loss of the relationship, some of the clinical features of dementia (i.e. cognitive, behavioural and emotional) are portrayed in films as affecting the ability of people with dementia to engage with other people and to maintain meaningful relationships. Dementia is sometimes portrayed as contributing towards conflict between other members of the family. However, in the film "A separation" (by Asghar, 2011), which portrays tension between a husband and wife, partly in connection with the care of the man's father who has dementia, in response to his wife's argument that the father no longer recognises him, he responds, "But I recognise that he is my father" which renders unnecessary the return of the memory of the relationships upon which the false hope of the "love miracle" rests (Sayem, 2012).

### ***Related ethical issues***

The portrayal of dementia in films often fails to portray people with dementia as active agents and in depicting a personal, inescapable tragedy, also in terms of their relationships with other people, this may lead to the objectification of people with dementia. If the various cognitive losses are interpreted by viewers as being linked to the inevitable pro-

gression of the disease, this may lead to reduced efforts to communicate with the person with dementia and a failure to consider other factors which might contribute towards the person's loss of various capacities. A vicious circle may then develop or a downward spiral, as described by Kitwood, involving increased isolation and neurodegeneration.

There is a need to be more open to different possible interpretations of the behaviour and capacities of people with dementia. For example, the observation that a person with dementia cannot accurately name a familiar person does not necessarily mean that s/he does not know or more importantly value that person. S/he may recognise the quality and value of his/her relationship with that person but be unable to put a name to the face.

The portrayal of dementia in films may also contribute towards the fear of dementia and thus contribute towards the stigma surrounding dementia as fear is a major contributing factor to stigma (Jones et al., 1984; Stangor and Crandall, 2003). Although it must be borne in mind that most films about dementia, which people watch at the cinema, are not documentaries, film producers are nevertheless advised to portray major health issues in as accurate a way as possible. Making a parallel to other major health concerns, there would be a public outcry if films were seen to be conveying misleading messages (e.g. that the consumption of alcohol and heroine by teenagers was harmless).

### 3. *The perception of those who are perceived and portrayed*

So far, we have examined the different ways that dementia is perceived and portrayed by different groups within society, including people with dementia themselves. Before concluding, we briefly consider the importance of the perceptions of people with dementia, how and what they are telling us about dementia and some of their reactions to the way that dementia is perceived and portrayed in society.

#### **Why the perspective of people with dementia is important**

The literature abounds with descriptions of the symptoms and progression of dementia, the impact of dementia on carers and issues related to the current and future provision and financing of dementia care. The focus is often on the challenge that dementia poses in medical, economic and social terms. In addition, dementia is typically perceived and portrayed as involving losses and evoking fear. The perspectives of people with dementia provide an inside account of dementia which is much richer than that typically portrayed by people who do not have it. People with dementia can tell others, who may one day have dementia, what it is like and what they need. This may influence how dementia is subsequently portrayed and help ensure the provision of appropriate and good quality care, support and treatment. In this context, Goldsmith commented,

*“It is necessary first to first accept that people with dementia have a voice that is worth listening to, second to facilitate the use of it and third to hear it.” (Goldsmith, 1996, ix)*

#### **How people with dementia are influencing how it is perceived and portrayed**

In the last few decades a number of people with dementia have written about their experience of having dementia (Boden, 1998 and 2005; DeBaggio, 2002; Davis, 1989; McGowin, 1993). Several have spoken about their experience of dementia at local, European and international dementia conferences. Recent examples include Peter Ashley, James McKillop, Helga Rohra and Nina Balackova. In addition to peer support groups for people with dementia, some groups of people with dementia (such as the Scottish Dementia Working Group, Dementia Advocacy and Support Network International (DASNI) and the European Working Group of People with Dementia) actively seek to communicate their experience and perceptions of dementia to wider society. In participating in research, especially qualitative research, people with dementia enable others to gain insight into their experience. Yet others have shared their experience and perception of dementia with healthcare professionals, service providers, school children and students, and in some cases, helped shape national dementia policy.

Early studies into the experience of dementia relied heavily on the interpretations and observations of relatives and carers. Cotrell and Schulz (1993) were particularly critical of this, stating that such studies reduced people with AD to “an entity to be studied rather than someone who can directly contribute to an understanding of the illness and its course” (Cotrell and Schulz, 1993, cited in Keady, 1996, p.277). Fortunately, this is less common nowadays although relatives and carers are still sometimes consulted on issues of relevance to people with more advanced dementia, even though researchers are encouraged to adopt approaches to maximise the potential of people with dementia to participate.

## What people with dementia are telling us about the experience of dementia

Some of the earlier personal accounts of dementia portrayed dementia as a fairly painful experience and as involving a struggle against cognitive decline. This was in keeping with the way that dementia was generally perceived. It may also have been influenced by a comparatively lower level of care and support, and fewer treatment options. However, people with dementia are increasingly portraying a more nuanced and to some extent more positive outlook on dementia.

Dementia is not universally considered as a devastating disease and some people in the early stages are even quite indifferent towards it (Steeiman et al., 2007). A small-scale qualitative study of eight older people with dementia found that the descriptions of the experience of dementia ranged from “not a big deal” to “hellish” (Hulko, 2009). One person described it as a nuisance whereas another stated,

*“You can fight it or try to overcome it or step around it, but it’s there and it’s not as if you can say that what a nuisance, I’ll push it aside and carry on uh, my regular, no you can’t. It’s just a. It is a different way of life. And you can roll with it or I suppose you could go and hibernate, uh tuck yourself away, but yes, it does make a difference.” (Hulko, 2009, p. 7)*

In contrast to the above perspective, one person with dementia described AD as something that was not constantly on his/her mind and the tendency to just carry on.

*“I don’t think every day, ‘oh gosh, I have got Alzheimer’s or something like that, I just carry on.” (Alzheimer’s Society, 2008, p. 52)*

The first of the above quotes is full of symbolism of fighting, stepping around or pushing aside an obstacle, sleeping through the experience or withdrawing from it. One person with dementia described the experience of other people with dementia as like living in a fog. Another person in the same study (Hulko, 2009) described the progression of dementia in terms of a journey across unknown territory, with the knowledge that the ground was becoming a slippery slope which might turn out to be steep or gradual. This shows how people can use metaphors to convey in symbolic form an experience, an emotional reaction and an approach towards living with dementia (e.g. to avoid or ignore it, to wait and see but to tread carefully due to the unknown nature of what lies ahead etc.). Although metaphors can sometimes be damaging when over-used, people with dementia sometimes find metaphors a helpful means to communicate their experience to others.

Whilst people with dementia often do not start from the assumption that dementia is “a problem”, many contemplate future changes and the progression of the condition. This may lead to worry but at the same time to the opportunity to make plans based on possible future scenarios. Some people with dementia, whilst not perceiving dementia as a problem, think that it may well be a problem for their families (MacQuarrie, 2005).

*“No, I don’t have any trouble with my memory. I don’t have any trouble with my memory! People, other people might have trouble with my memory, but I don’t have any trouble... As far as I am concerned, Alzheimer’s is not bothering me at all.” (MacQuarrie, 2005)*

Contrary to the common perception that people with dementia have no quality of life, people with dementia do not tend to rate their quality of life as poor. Of 88 people with mild to moderate dementia, 67% reported having a good quality of life and this was in part linked to having a sense of being useful (Cahill et al., 2004). However, Droës et al. (2006) point out that being of use was not mentioned by carers as being relevant to quality of life and Gerritsen et al. (2007) found that professional carers only focused on it to a minor degree. The importance of feeling useful and being able to give something back also runs counter to the common perception of people with dementia being unable or unwilling to reciprocate, which was one of the frames identified by van Gorp et al. (2012) and one of the themes which emerged from a study into GPs' perceptions of dementia (Gove, 2012). In her opening address to the members of the European Working Group of People with Dementia (EWGPWD), Helga Rohra highlighted the importance of reciprocity, stating that "people with dementia want to give something to the people around them, not only to take". Subsequent discussions within the group revealed the shared perception that having dementia did not take away the ability to contribute towards society and that the ability to do so was important for self-esteem and quality of life. Whilst not suggesting that dementia is a wholly positive experience, members of the EWGPWD emphasise that they still have a place and a role to play in society and wish to focus on maximising their remaining capacities and on what is positive in their lives, and that this calls for appropriate services and support, as well as a timely diagnosis, to maximise the potential of people with dementia to lead fulfilling lives.

### **Do we really hear what people with dementia are telling us?**

More and more people with dementia are stepping out of their comfort zones, standing up in public and speaking about their personal experience in front of hundreds if not thousands of strangers. It is important to listen to them and hear what they are telling us. Sometimes, people listen but misinterpret what was said as it does not correspond to their perception of dementia. For example, statements made by people with dementia (e.g. to the effect that they don't have a problem with memory as in the above quote) may be interpreted as involving denial (deBoer et al., 2007). Whilst denial may occur and some people with dementia may lack insight, what people with dementia say is interpreted in the light of our perceptions and assumptions about dementia which may sometimes be inaccurate, biased and misguided.

A discrepancy between what a person with dementia says or does and people's expectations of what is "normal" or "usual" for people with dementia may even result in people concluding that a person must not have dementia. Nina Balackova, who has dementia, explained at a recent conference that her ability to recite accurately all the names of the presidents of the United States of America (a task which took weeks of practice) led to a specialist declaring that she must not have dementia. Yet achievements based on remaining capacities, as well as on effort and practice, and the loss of certain capacities, differ from one person to the next. Daphne Wallace (2013), who has dementia, points out that the losses which might occur as a result of dementia are subjective and dependent on what the person concerned considers important and normal for him/her. If we listen to people with dementia but only hear what fits comfortably in with our existing understanding of dementia, we will not gain more insight into this condition.

Finally, it must be borne in mind that the perceptions of dementia held by some groups within the overall population with dementia are not equally heard and in some cases not

heard at all (Hulko, 2004 and Phinney, 2008 in Alzheimer Europe, 2011). Whilst people have multiple identities, the perspectives of some groups of people with dementia, such as those who are lesbian, gay, bisexual or transgender (LGBT), have Down's syndrome or are homeless, in prison, travellers or physically disabled, are notably absent and the perspectives of others, such as those who are, for example, middle-class, well-educated and in the earlier stages of dementia are more present.

### Reactions of people with dementia to the way that dementia is perceived and portrayed

Some people with dementia (such as Peter Ashley, James McKillop and Bryden to name but a few), who have spoken at dementia conferences, have objected to the way that dementia and people with dementia are perceived and portrayed (e.g. as empty shells, people with no mind as the term "demented" implies, people who are suffering and people who are dying from dementia).

People with dementia have also challenged the perception and portrayal of dementia as a stigma. Terry Pratchett, for example, a well-known British fiction writer, recently diagnosed with a rare form of dementia, expressed his view that dementia is not a disease of the bumbling elderly and claimed that people with dementia are stigmatised as "superfluous old farts" (Alzheimer Europe, September 2008). Mr Jan Henry Olsen (a former Norwegian fisheries minister who has dementia) stated at a dementia conference in Oslo that he sometimes feels like a criminal even though he knows he has committed no crime. He used the term "taboo" to describe how people sometimes react towards him and his wife since he has been diagnosed with dementia. He described his experience of misguided health professionals trying to "keep it (the diagnosis) quiet" but also how this had motivated him to challenge such stigmatization (Alzheimer Europe, DIE Magazine, June 2008).

The portrayal of dementia in the UK awareness raising campaign as a condition which results in people gradually fading away, as well as to a song about dementia including the words "No one and nothing can bring you back to me", aroused strong objections from some of the members of the EWGPWD. In relation to the television campaign, Daphne Wallace commented, "As I said in a large meeting earlier this year, I have yet to find anyone with dementia who likes this advert and many friends, even with little knowledge of dementia are also critical of it." Helga Rohra, commenting on the song, was outraged that people with dementia could be portrayed in what she considered to be a misleading way and as "inanimate objects".

Whilst some forms of communication can be described as strategic (see separate section on this topic), the way that dementia is portrayed is often based on good intentions but sometimes accompanied by a lack of information or suitable reflection. It is therefore important that people with dementia continue to provide feedback about their experience of dementia and of the way that it is portrayed in order to ensure that dementia is perceived and portrayed in a balanced way, thus avoiding "doom and gloom" scenarios or looking at dementia through rose-coloured spectacles.

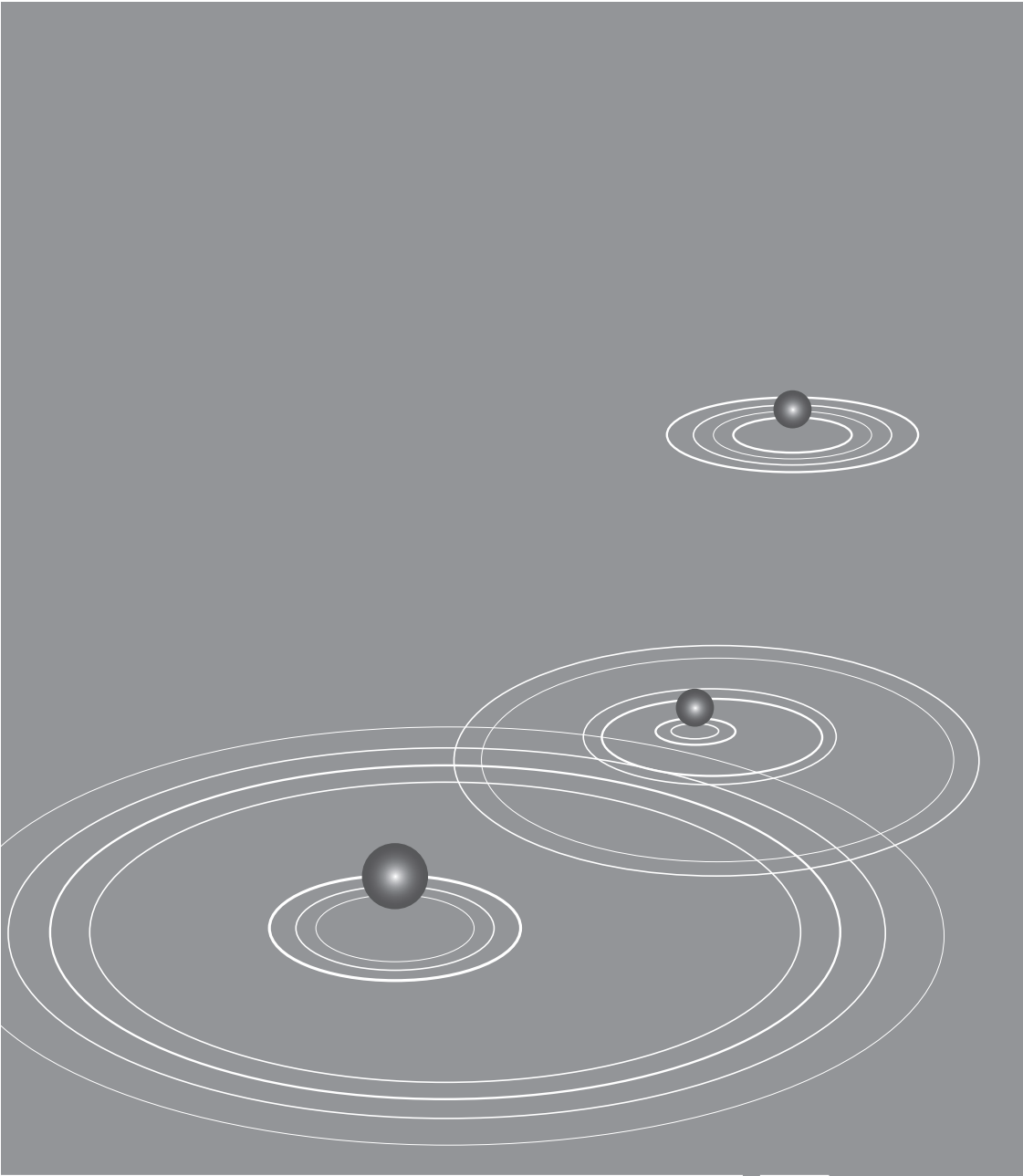
#### 4. *Concluding remarks*

We have presented a vast array of perceptions and portrayals of dementia in this report and have reflected on their possible impact on people with dementia in many different ways (e.g. in terms of how they might affect people psychologically and emotionally, how they might affect relationships, roles, rights and the responsibilities of everyone in society). Looking back over the different sections, it becomes clear that often the consequences of a certain way of perceiving or portraying dementia may be beneficial in some ways, and potentially harmful in other ways, and that this can depend on the time, the situation or context, the people involved, what is at stake, personal factors and issues linked to the social, political, economic and cultural climate. We learn from each other and from experience with the result that what seems appropriate and “normal” today might seem outrageous in years to come. For these reasons, we will not conclude with a set of instructions on how to perceive and portray dementia and people with dementia. Apart from the fact that this would be presumptuous on our part, we do not have all the answers. Moreover, whilst we can learn a great deal from reflection and experience, it is important to implement the results of these in the constantly changing real world and in relation to real people with dementia. For this to be possible, we need to ensure that people with dementia remain an integral part of our social worlds/society and that they and their views are valued. To conclude, we now present a list of guidelines for reflection linked to the perception and also the portrayal of dementia.









*Guidelines*



## *Guidelines for reflection linked to the perception of dementia*

In the following guidelines, the term “perception” is used to refer to the ideas, beliefs, mental images, feelings and thoughts that we have about dementia and people with dementia.

- Look beyond the dementia to the person. Dementia is just one aspect of a person’s identity.
- Avoid thinking in terms of “us” and “them”. People with and without dementia are all part of the same society.
- Try to consider people with dementia as the same people as before they had dementia.
- Be attentive to what people with dementia are saying about their experience.
- Acknowledge the diversity of people with dementia.
- Strive for a nuanced perception of dementia.
- Pay attention to positive images such as people with dementia enjoying life, interacting with others or involving themselves in community, social and political life.
- Be aware that people with dementia have something to offer
- Avoid dichotomous thinking about dementia and considering people with dementia as “the problem”.
- Avoid generalising about the experience and impact of dementia on the basis of limited information.
- Bear in mind that media accounts, articles, films and even documentaries offer a particular perspective of dementia and not the only “truth” about it.
- Reflect on whether your perceptions of dementia are based on, or result in, certain unfounded assumptions.
- Consider to what extent the mental images you have of people with dementia are perhaps influenced by negative stereotypes or clichés.

## ***Guidelines for reflection linked to the portrayal of dementia***

In the following guidelines, the term “portrayal” is used to refer to the words, images and any form of representation which results in the possible communication of information or feelings about dementia and people with dementia.

### **Be respectful**

- Convey respect for people with dementia through your choice of words and images.
- Ask yourself how you would like to be portrayed if you had dementia.
- Reflect on ways to capture the dignity, personhood, individuality and citizenship of the people you are portraying.
- Avoid portraying people with dementia as “other”, fundamentally different or inhuman.
- Avoid reducing people to numbers, objects, medical cases and problems.

### **Provide a nuanced image of dementia and people with dementia**

- Strive for a balanced portrayal of dementia which acknowledges achievements and remaining capacities as well as losses and difficulties.
- Familiarise yourself with different frames, use them when appropriate with caution and do not hesitate to propose a counter-frame.
- Avoid portraying dementia in a way that is deliberately alarmist, frightening or based on stereotypes and clichés.
- Don’t hide aspects of dementia which people may find disturbing but put those aspects into perspective and context. Show how those aspects of dementia are part of a much bigger picture which is not all negative.
- Show how dementia affects people in different ways.
- Portray people with dementia from a wide range of sub-groups within society and from all walks of life.

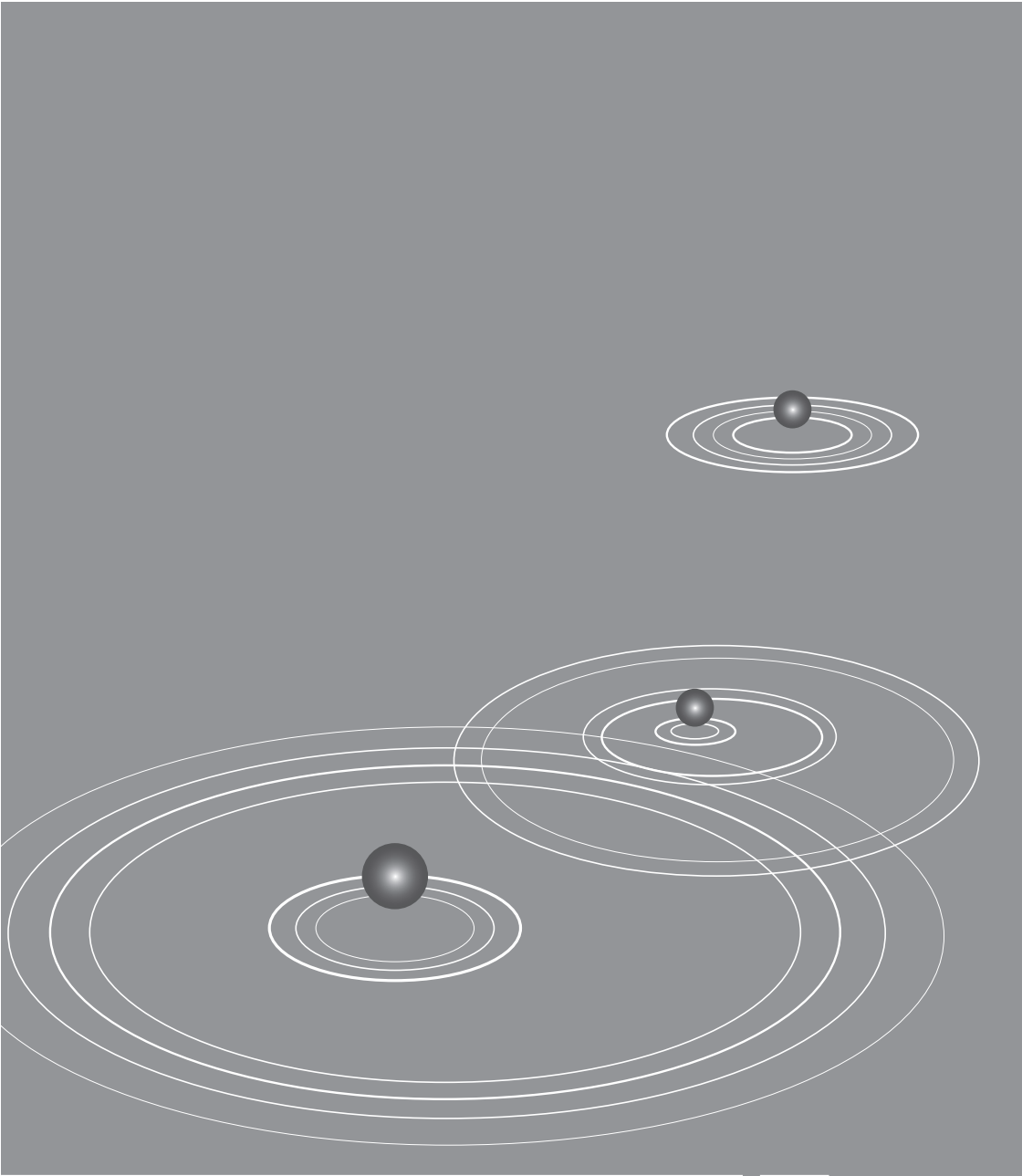
### **Inform yourself and others**

- Make an effort to talk to people with dementia and to obtain their feedback with regard to the issues you intend to portray or report.
- Know your facts and figures as well as the overall topic.
- Put facts and figures into perspective and give your target audience the means to access more information should they require it.
- If portraying a certain aspect of dementia which some people might find disturbing, provide details of an Alzheimer Association or other organisation where they can obtain support.

### **Be aware of what you and others are communicating**

- Consider not only the message you wish to communicate but also the different possible ways it might be interpreted.
- Question your own assumptions about dementia.
- Choose your words, metaphors and images carefully.

- Consider what the words you use when talking about dementia or people with dementia imply and whether you personally agree with those implicit assumptions.
- When communicating for a particular reason to a particular audience (i.e. strategically), reflect on how people with dementia might feel about your portrayal.
- Reflect on how people with dementia are portrayed by others, what kinds of messages are being communicated and possible reasons for trying to convey a particular perspective.
- Be prepared to challenge the way dementia is portrayed if you feel that it is inaccurate, disrespectful or misleading.



*Appendix 1*  
*Details of the*  
*working group*

**Debby L. Gerritsen**, PhD, is psychogerontologist and senior researcher at the Department of Primary and Community Care of the Radboud University Medical Centre, Nijmegen, in the Netherlands. Her research interests include quality of life, mental health and psychosocial interventions for people with dementia and long-term care residents. She is a member of Interdem, a pan-European research group on detection and timely INTERvention in DEMentia.

**Bénédicte Gombault** is a project manager at the King Baudouin Foundation in Belgium and senior project manager for the projects on dementia. She has a special interest in the legal and ethical aspects related to Alzheimer's disease and in the communication and the social representations of dementia. She has contributed to various projects and publications of the KBF about dementia and was member of the Executive board for the ALCOVE joint action (Alzheimer Cooperative Valuation in Europe).

**Dianne Gove**, PhD, is Director for Projects at Alzheimer Europe and Chair of the European Dementia Ethics Network. She has directed several projects in the field of dementia related to ethical issues, legislation, assistive technology and care and recently obtained a PhD for her research into the stigma of dementia. Prior to this she obtained a BSc Honours degree in Psychology and MAs in Psychoanalysis and Education before training in analytical Gestalt therapy.

**Fabrice Gzil** (PhD in Philosophy, Université Paris Panthéon-Sorbonne, 2007) is programme manager at Fondation Médéric Alzheimer (Paris, France), a non-profit organization committed to helping people with dementia and their carers through the support given to selected innovative projects and social science research, as well as national and international watchdog activities. His research focuses on the promotion of the autonomy and dignity of people with dementia. A chapter of his recent book "La maladie du temps" addresses the status of dementia and Alzheimer's disease in society.

**Jana Kasparkova** is a nurse and was Assistant Professor of Nursing at the Faculty of Medicine of Charles University in Pilsen for 10 years. She is currently a PhD student in the Faculty of Humanities of Charles University in Prague in the Applied Ethics programme. Her research is focused on ethical dilemmas in the care of patients with Alzheimer's disease.

**Jan R Oyeboode**, M Psychol. (Clinical), PhD, is professor of dementia care in the Bradford Dementia Group, University of Bradford, UK. She is a clinical psychologist who has worked in the British National Health Service with people with dementia for many years, as well as researching. Her research interests include the subjective experience of dementia in the family, especially in relation to young onset dementia and the cultural context.

**Sirpa Pietikäinen** (MSc in Business from the Helsinki School of Economics) is a Finnish member of the European People's Party (EPP) in the European Parliament where she is the first Vice-Chair of the Internal Market and Consumer Protection Committee, and substitute Member in the Economic and Monetary Affairs Committee and the Women's Right and Gender Equality Committee. She is a member of the Alzheimer Europe Board, as well as Vice-President of the Council to the Finnish Memory organisation and lectures at university on negotiations theory and practices.

**Christine E. Swane** (PhD in Cultural Gerontology, University of Copenhagen, 1996) is Director and responsible for research at the foundation EGV which targets research and

projects concerning older people's social life. She has published many books, reports and articles, primarily in Danish, about everyday life with dementia and cultural perspectives including stigma and perceptions, and special care and day care facilities.

**Aino Valtanen** (MSc in Political Science) is working as parliamentary assistant to the Member of the European Parliament, Sirpa Pietikäinen. She has worked since 2010 and focuses mainly on social and health policies, including ageing policies.

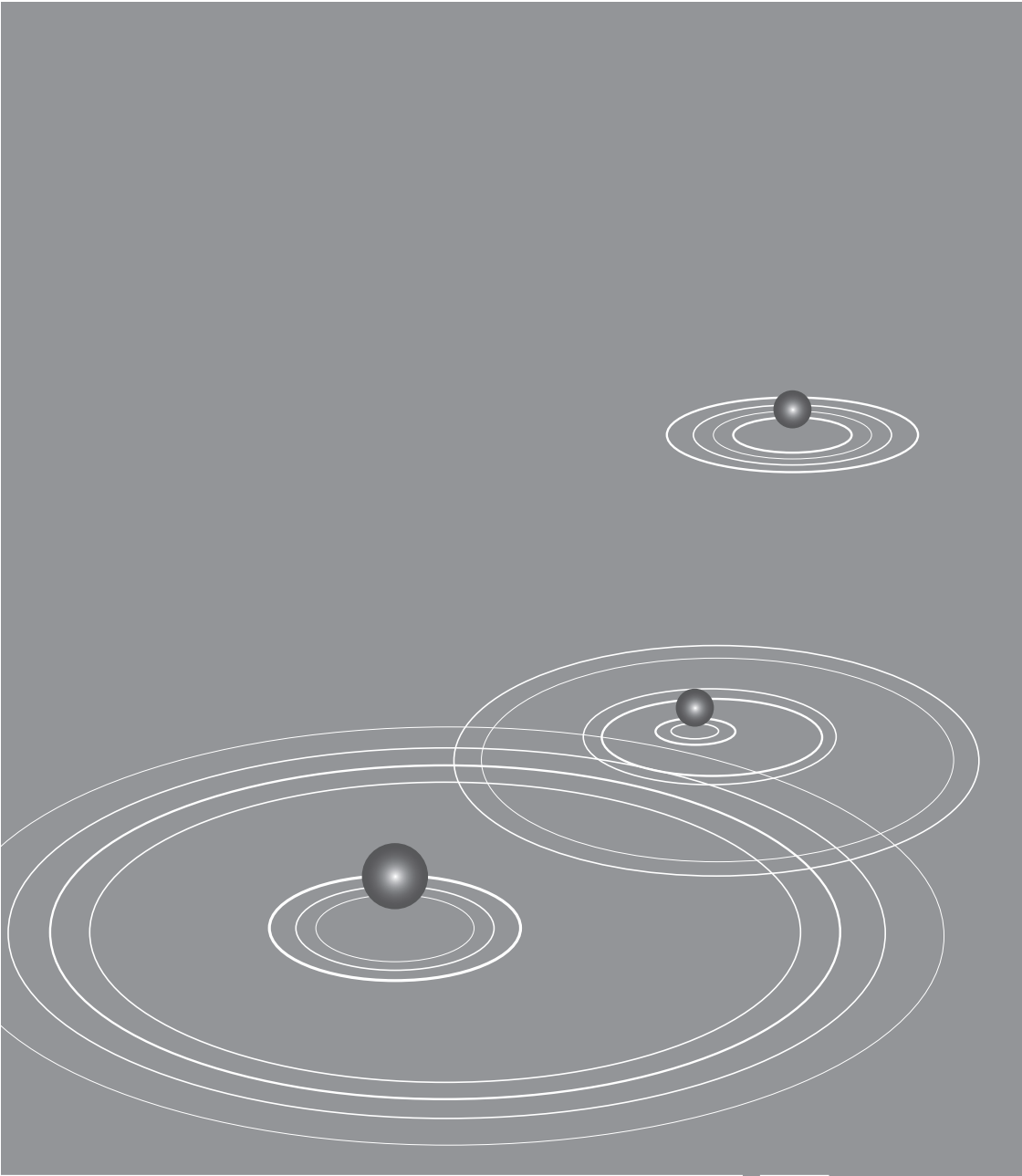
**Baldwin Van Gorp** (PhD in Political and Social Sciences, U of Antwerp, 2004) is an associate professor of journalism and communications management at the Institute for Media Studies of KU Leuven, Belgium. His research interests include the framing concept, journalism ethics and representation. He previously published studies on the framing of the elderly and the framing of dementia.

**Daphne Wallace** (MB ChB FRCPsych DPM Dip.Psychother) studied Medicine at the University of St Andrews and specialised in Psychiatry. She is a member of the European Working Group of People with Dementia, which was set up in 2012 by Alzheimer Europe. Since her diagnosis with vascular dementia, she has campaigned for the rights of people with dementia and has been involved in research projects related to the rights and care of people with dementia. She was also a Trustee of Alzheimer's Society UK for 12 years and is now an Ambassador for the Society.

**Richard Wallace** was a student at Oxford University. Having lectured in philosophy for some years, he then trained for ordination in the Church of England. For 5 years, he was Chaplain at Bradford University and then in Parish work in the Diocese of Bradford. He is now retired. Richard has some experience of being a befriending visitor for the Alzheimer's Society. He was previously a carer for his mother who had dementia and now helps Daphne.







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