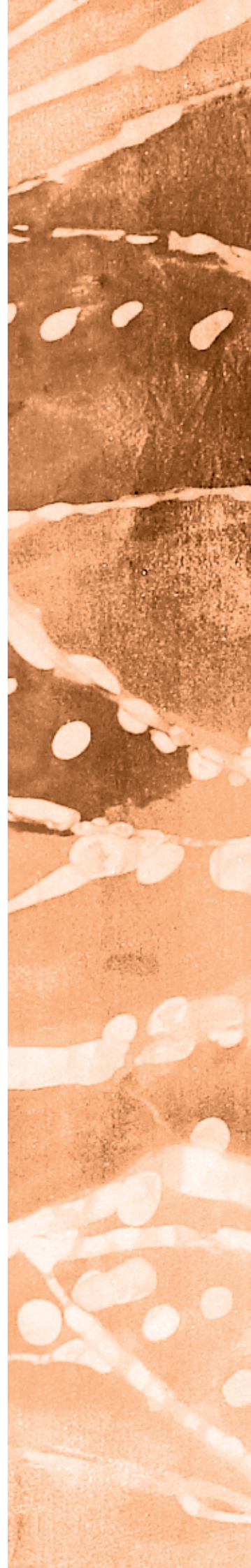


# Chapter 2

An ethical framework



## Chapter 2 – An ethical framework

### Introduction

- 2.1 This Report focuses primarily on those ethical issues that are faced by people with dementia themselves and by those directly involved in caring for them. Ethical issues arise, however, for all of us. This is because we all face the possibility of dementia ourselves, and because as members of society we are involved in questions about attitudes towards dementia and about how best those with dementia and their carers should be supported.
- 2.2 Ethics is concerned with questions about the morally right thing to do. In many situations it may be clear what it is right to do. In other situations, however, there may be several options, none of which is unambiguously right. Such situations create an ethical dilemma for the person making the decision. Different ethical values may point to different courses of action, and deciding on which course to take involves judgment in deciding how much weight to give to each value. There are many examples in this Report of problematic situations that pose ethical difficulties for those involved in the care of people with dementia.
- 2.3 In ordinary conversation, people often think of ethical issues primarily in terms of ‘large’ issues, such as end of life decisions, or in connection with sexual behaviour. In this Report the ethical discussions are not limited to these larger issues. Indeed the view taken in this Report is that ethical questions arise very frequently in the ordinary day-to-day care of people with dementia. Carers (families, friends and neighbours providing unpaid care) are making ethical decisions almost every day: how to balance safety with freedom; deciding what is in the best interests of the person with dementia; and balancing the needs of the person with dementia with those of others, including the carers themselves. Care workers and professionals working with people with dementia face similar challenges.
- 2.4 Ethical issues, whether faced by carers, care workers, professionals or society, arise in specific situations, and the relevant ethical judgments must be made in the light of each particular situation. Ethical judgments should not be arbitrary: they should be based on general values, and those values need to be applied to the specific situation. It is rarely possible, however, simply to deduce from general values the (ethically) right thing to do in each specific situation: ethical judgments are too complex and uncertain. It is, nevertheless, important to provide some structure – an ethical framework – if ethical judgments are to be based on a sound foundation. In this Chapter we propose an ethical framework to help those who face ethical problems in the context of dementia. We explain the framework in considerable detail because the details may help those providing care to make decisions in some of the ethically problematic situations that they face. The framework also underpins the discussions of ethical questions throughout this Report.

### The origins of our ethical framework

- 2.5 The framework that we propose has six components: a methodology for approaching ethical decisions; beliefs about the nature and impact of dementia; and a set of interlinked ethical values. These are listed in Box 2.1 below and explained more fully in the rest of this Chapter.

**Box 2.1: Dementia: an ethical framework**

- Component 1:** **A 'case-based' approach to ethical decisions:** Ethical decisions can be approached in a three-stage process: identifying the relevant facts; interpreting and applying appropriate ethical values to those facts; and comparing the situation with other similar situations to find ethically relevant similarities or differences.
- Component 2:** **A belief about the nature of dementia:** Dementia arises as a result of a brain disorder, and is harmful to the individual.
- Component 3:** **A belief about quality of life with dementia:** With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.
- Component 4:** **The importance of promoting the interests both of the person with dementia and of those who care for them:** People with dementia have interests, both in their autonomy and their well-being. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values. Autonomy is not simply to be equated with the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning. The separate interests of carers must be recognised and promoted.
- Component 5:** **The requirement to act in accordance with solidarity:** The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole.
- Component 6:** **Recognising personhood, identity and value:** The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.

2.6 We have developed our framework in order to respond to the particular dilemmas and difficulties which arise as a result of dementia. The framework draws on existing, widely used approaches to health care ethics. Although there are many different approaches to health care ethics, the value placed on factors such as a person's wishes, values and general well-being, and on broader factors such as some sense of fairness or justice, are common to all.<sup>86</sup> Thus, while our framework is not dependent on any single approach to ethics, it is compatible with other mainstream approaches.

**Component 1: A case-based approach to ethical decisions*****Sound moral judgments***

2.7 Determining the right thing to do in an ethically complicated situation is difficult, and often there is more than one ethically defensible answer to a given question. This is certainly the case for some of the difficult problems presented by dementia and raised by respondents to our consultation. However, we think that 'sound moral judgments' have a number of features, and that a consideration of these features can provide a useful methodology for ethical deliberation.<sup>87</sup> This methodology has three main stages: identifying and clarifying the relevant factual considerations; interpreting and applying appropriate ethical values; and comparing with other similar situations. We describe each of these stages in turn below, and then consider the additional support that those having to make difficult ethical decisions may need in order to cope with the difficulties they face.

**Identifying and clarifying relevant factual considerations**

2.8 Sound moral judgments are always based upon the careful consideration of the background factors that are relevant to the particular decision. Consider a 70-year-old man, Mr P, living with

<sup>86</sup> Respect for autonomy, for example, is highlighted as one of the four key principles in the widely-used text by Beauchamp and Childress (Beauchamp TL and Childress JF (2009) *Principles of Biomedical Ethics*, 6th Edition (New York and Oxford: Oxford University Press)). It is also central in both Kantian and utilitarian approaches to ethics although for very different reasons.

<sup>87</sup> Our account of an approach to sound moral judgments is based upon Jonsen and Toulmin's account of casuistry in Jonsen AR and Toulmin S (1988) *The Abuse of Casuistry: A history of moral reasoning* (Berkeley: University of California Press); Jonsen A (2007) Casuistical reasoning in medical ethics, in *The Principles of Health Care Ethics*, 2nd Edition, Ashcroft R, Dawson A, Draper H and McMillan J (Editors) (Chichester: John Wiley); Jonsen A, Siegler M and Winslade W (1998) *Clinical Ethics* (New York: McGraw-Hill). However, the approach described is not unique to a 'casuistry'-based approach.

his daughter. When his daughter is cooking, Mr P frequently joins her in the kitchen and gets in the way of the cooking. Mr P's daughter is tempted to lock the kitchen door whilst she is cooking to prevent Mr P from entering, but she is not certain whether this is the right thing to do. The relevant facts to consider include: the degree of danger and distress to Mr P when the kitchen door is locked; the length of time he remains distressed after the cooking is finished; the danger if Mr P is in the kitchen; the effect on his daughter of his being in the kitchen during cooking, and the extent to which this interferes with the cooking; what Mr P would have thought about this situation had he considered it before the onset of dementia; and what he is currently able to understand.

### **Identifying, interpreting and applying relevant ethical values**

2.9 Sound moral judgments also involve the consideration of ethical values. For Mr P, general considerations about the importance of autonomy and well-being (see paragraphs 2.26–2.39) need to be interpreted and applied. At first it might seem that concern for Mr P's autonomy would favour allowing him into the kitchen, since locking the door restricts his freedom and his behaviour suggests that he wants to be in the same room as his daughter. This may be too simplistic, however, because Mr P's previous wishes, at a time when he would have understood all the relevant issues, might have favoured enabling his daughter to get on with the cooking unimpeded. Factors affecting Mr P's well-being, such as avoiding harm, also need careful consideration. Finally, the interests of Mr P's daughter are also relevant, both because Mr P's well-being is closely bound up with that of his daughter and because her well-being is of ethical significance in its own right.

### **Comparison with similar situations**

2.10 A third feature of sound moral judgments is they often involve comparison with other similar cases where it has been clear what is the right thing to do ('sentinel' or 'paradigm' cases). When someone faced with a difficult ethical situation has identified the relevant considerations and ethical values, then they can weigh these in the balance and reason on the basis of past experience of similar cases. For example, Mr P's daughter might already have had to make a decision about whether or not to leave her father in the house alone whilst she goes shopping. Her deliberation and conclusions in that situation may be highly relevant to the issue of whether to lock the kitchen door. A health professional such as a community nurse might be able to help the daughter by comparing her situation with that of other families, advising on what has worked elsewhere, and perhaps also by identifying a solution which may remove the problem altogether. In other words, one difficult decision can be compared with another decision where the issue has already been decided. Sometimes this will be easy, if the paradigm case and the present one are very similar; but sometimes there will be both similarities and relevant differences. Yet it might still be helpful to ask: if it is right to lock him in the house when I go shopping, why is it not right to lock him in a part of the house when I am cooking? However, sometimes previous conclusions may have to be revised in the light of new ways of seeing things or new evidence: such a comparison might lead the daughter to decide that it is not right to restrict her father's movements in either of these situations. We return in more detail to quandaries such as these in Chapter 6 (see especially paragraphs 6.28–6.38).

### ***Education and support in ethical decision making***

2.11 Legal frameworks and guidelines can often be helpful in guiding practice and decision making, but they need interpreting and applying to specific situations: rarely will a law or guideline provide a sufficiently precise answer to a particular problem, and there are dangers in applying them too rigidly. Some judgment needs to be exercised by those who face these ethical difficulties. Laws and

guidelines should support those making decisions, but they should not become a straitjacket and prevent sensible judgment.

- 2.12 It is therefore not enough, in giving support for the ethical issues that arise for carers, care workers and professionals alike, to provide only guidelines. Skills, as well as knowledge, are required to respond appropriately in these difficult circumstances. If professionals and care workers are to be supported in developing these skills and making decisions about the ethical problems that they face, then they will need both continuing education and forums in which they can discuss and share with others their concerns and approaches. If professionals are to be able to support others, such as carers, in the ethical issues they face, then they will also need ongoing education in how to do this. Crucially, carers will need access to both peer and professional support to enable them to respond to the ethical problems that arise in their lives on a daily basis. We return to the issue of such ongoing education and support in Chapter 7.

### Component 2: The nature of dementia

**“As with other disabilities [dementia] can be the occasion of positive changes and opportunities, but these should not be romanticised. [...] Dementia is a harm. Nevertheless, while dementia is a form of disability the person with dementia is still a person to whom respect is due.”** *Professor David A. Jones, consultation respondent*

- 2.13 Dementia arises as a result of a brain disorder, and people are harmed at some point by having dementia. This statement may seem so obvious as not to need stating but there were some views put to us in the course of our consultation that challenged this belief.<sup>88</sup> For example, it was suggested that if we value the state of having dementia negatively by considering it a disorder, then we are also valuing people who have dementia negatively. It was also argued that with good care people with dementia should be able to have as good a quality of life as people without dementia; and that dementia is on a continuum with normal ageing: that is, the brain degeneration inherent in dementia is within the normal range for brain ageing.
- 2.14 We reject these three points as grounds for concluding that people are not harmed by having dementia. First, we reject the idea that valuing the state of dementia negatively is the same as valuing the person with dementia negatively. We believe (as we discuss further in paragraph 2.53) that people with dementia should be valued just as much as people without dementia. The state of having dementia is, nevertheless, a harm, and one implication of our position is that if a person could be cured of dementia, or prevented from developing dementia, then in general that would be desirable. By analogy, we can regard the state of having diabetes as a disorder, value it negatively, and aim to prevent and cure diabetes, without in any way valuing people with diabetes themselves in a negative way.
- 2.15 With regard to the second point, we doubt whether, even with good care, most people with dementia can enjoy as good a quality of life as they enjoyed before they developed dementia. This issue depends on what we understand by ‘quality of life’. As we will argue later, a person has interests in the promotion of both their well-being and their autonomy. A person with dementia will not be able to exercise their autonomy to the same extent as prior to the dementia. This represents a harm, regardless of the quality of care the person receives. To deny this would imply that causing brain damage leading to dementia (in a previously healthy person) would not be harmful so long as the person then received good care. Again there is a useful analogy with diabetes. There is a mild state of diabetes where symptoms do not necessarily interfere with having a good quality of life even if the disorder (in the pancreas) is ignored. But at some point the disorder in the pancreas

<sup>88</sup> For example, in the Working Party’s fact-finding meeting on 29 July 2008, with members of the Bradford Dementia Group.

(like the disorder of the brain in dementia) will intrude and affect the person's life in a harmful way. Good quality care will ameliorate this harm; but this does not contradict the view that the disorder is a harm. Of course none of what we have stated takes away from the importance of providing as good care as possible for people with dementia.

2.16 With regard to the third point, although some neurobiologists consider that dementia is on a spectrum with normal ageing, we take the view that dementia is distinct from ageing (see paragraph 1.30). However, on either view, it is still desirable to prevent or ameliorate its effects. Moreover, we note that the provision of a 'label' for a condition is often the first, and necessary, step for appropriate care and support to be provided.

2.17 There are three key implications of our belief that dementia is a harm:

- Research into finding ways to prevent or cure dementia, and improve the quality of life of people with dementia, is important, and should be properly resourced (taking into account the prevalence of dementia).
- Reducing cognitive and other impairments, or slowing the rate of their decline is valuable, although any negative effects associated with such reduction or slowing (such as increased distress on the part of the person about their cognitive abilities) need also to be taken into account.
- When decisions about resource allocation are made, the dementias should be considered as diseases or illnesses in just the same way as are, for example, the various forms of cancer. Although the question of how society should resource care is beyond the remit of this Report, considerations of justice lead us to conclude that in allocating resources to alleviate the problems that arise as a result of dementia (such as difficulties with self care and the need for support from others in order to achieve a good quality of life), there should be no fundamental difference between those problems and, for example, responding to pain in cancer or mobility difficulties in arthritis. People with dementia should not be disadvantaged by the fact that social care interventions rather than health care are sometimes the appropriate way of helping with the problems that arise as a result of the dementia, nor by the different funding arrangements between social and health care. The need for care, whether social care or health care, is a direct result of the brain disorder.

### Component 3: Quality of life in dementia

2.18 Two contradictory approaches to the quality of life people may experience with dementia emerged in the responses to our consultation. One view is that having dementia is so bad that it would be preferable to be dead. Some of those who held this view supported legalising forms of assisted dying for those with dementia who had expressed wishes in advance to that effect. A related position is that it is not a good use of resources for society to put a great deal into the care of people with dementia. It would be better to try to develop laws and practices that facilitate assisted dying, reducing the length of time overall that people live with the condition.

2.19 The contrary view, expressed by many, including those with a great deal of experience caring for people with dementia, was that with good care one can hope, and indeed expect, that people with dementia will have overall a positive quality of life. Some believed that the quality of life with dementia can be just as good as without dementia.

2.20 Without wishing in any way to romanticise dementia, we strongly endorse a version of the second position: that quality of life with dementia can, given proper care, be positive overall for most people, even though the onset of dementia will inevitably lead to the loss or diminution of some valued aspects of a person's life. We note, for example, a research study in the United States of America where 21 out of 23 people with early-stage dementia characterised their current quality

of life as 'good' or 'better', despite the fact that most needed some assistance with daily life as a result of their dementia.<sup>89</sup>

- 2.21 The controversy over this issue is a combination of claims about values and claims about facts. At first sight it might seem that the disagreements relate solely to facts, even if the facts are difficult to determine: that is, is the experience of a person with dementia overall positive or negative? But this is over-simplistic because the experiences of people with dementia vary greatly both between people and at different stages for each person. It is also simplistic because a person's experiences will depend on the care and encouragement they receive, and that care will itself be affected by the views that carers, and society more generally, have towards the possibility of positive experiences.
- 2.22 More profoundly, those who claim that it would be better to die than to have dementia, do not normally make this claim on the basis of what the actual experience of dementia is like, but rather on the basis of how they *value* certain kinds of experience. In this context it is helpful to distinguish empirical claims about the experiences of people with dementia from value claims. One value claim is that in order for life to be worth living it is necessary not only to be generally happy but also to have a certain level of reflective and deliberative awareness. According to this value judgment, even if a person with dementia is generally happy, perhaps enjoying simple pleasures, such a life is still lacking in value because of the loss of the ability to reflect and deliberate.
- 2.23 We reject this view for three reasons:
- We believe that a person's life is of value even if they are severely cognitively impaired (see also paragraph 2.53). We do not endorse the view that a life in which a person is cognitively impaired and is experiencing severe behaviour changes is worse than no life at all, even if such developments represent an enormous change from the person's previous functioning. In other words we reject the view that life is worth living only if there is a certain level of reflective and deliberative awareness.
  - The question of whether the life of a person with dementia is worse than death depends, in our view, mainly on the nature of the person's day-to-day experiences. This we accept is an area of uncertainty.<sup>90</sup> It is important that further research is carried out to develop methods for determining the quality of these experiences for people with dementia, and we return to this point in Chapter 8. We expect that there is much variation in the quality of these experiences between different people with dementia, and that the experiences will depend crucially on the quality of care. We have been impressed by the evidence of many people and organisations that if skilled support is given to people with dementia and their families, then people with dementia (and their families) can generally have a positive quality of life. Their quality of life is particularly dependent on their relationship with their carers. 'Strange' behaviour, forgetfulness and repetitive questions by the person with dementia may lead to irritation and aggressive responses from carers, and such irritation is likely to be exacerbated if carers fail to understand or accept the changes the person with dementia is experiencing. Quality of life, then, is an issue that is strongly dependent on the relationship between the person with dementia and their carer, and on the carer's understanding of the effects of dementia.
  - The view that one takes on this issue is in part about the question of what is worth pursuing. One likely consequence of believing that life with dementia must inevitably be negative is that it is not worthwhile for society to put much effort into improving the lives of people with dementia. This negative valuation might suggest that we should be trying to find ways of ensuring that

<sup>89</sup> Katsuno T (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life *Ageing & Society* 25: 197–214.

<sup>90</sup> See, for example, Edvardsson D, Winblad B and Sandman PO (2008) Person-centred care of people with severe Alzheimer's disease: current status and ways forward *The Lancet Neurology* 7: 362–7.

people with dementia will soon die. Such a negative valuation is in danger of becoming a self-fulfilling prophecy: the negative valuation leads to indifferent care; indifferent care leads to a poor quality of day-to-day experiences; and the poor quality of experiences provides grounds for the negative valuation. We believe that this approach is wrong. The positive view that we endorse provides an impetus and reasons to try and maximise the positive features, including the quality of day-to-day life, for people with dementia.

#### Component 4: Promoting interests in autonomy and well-being

2.24 Three sets of interests are of particular importance: the interests of the person with dementia; the interests of carers; and the interests of care workers and professionals. These sets of interests are often closely connected. We will consider first the interests of the person with dementia.

##### *The interests of the person with dementia*

2.25 We highlight here two aspects of the interests of the person with dementia: autonomy and well-being.

##### **Autonomy**

2.26 Autonomy is often defined as 'self-rule', 'making your own choices', 'ability to live independently' or 'right to self-determination.'<sup>91</sup> Respect for individuals' choices and the promotion of independence are important principles in the care of dependent people, including those with dementia. But what does the right to self-determination mean for people with dementia, particularly when they are highly dependent on the care of others?

2.27 The concept of autonomy is often used to emphasise the freedom to make choices, and 'freedom' may be understood in the sense of 'having no interference' or 'not being hindered by others.' This aspect of autonomy is important in promoting the general right of individuals not to be interfered with against their wishes and provides a basis for the right to information, the right to give or withhold consent to treatment, and the protection of privacy. These are important and enduring moral values in our health care system, and they apply to the care of people with dementia as well as to people with full capacity to make decisions for themselves.

2.28 In the setting of dementia, however, (as in many long-term care settings) this notion of autonomy as 'no interference' is not sufficient. Indeed, if it is not part of a broader notion of autonomy it can be dangerous: it may be interpreted as a 'right to be left alone', degenerating into neglect. Legal norms apparently aimed at promoting autonomy, in this negative sense, can sometimes affect the relationships between professionals and patients, leading practitioners to adopt defensive attitudes and limit their services to care which is immediately necessary or for which patients have given their explicit consent. A person with dementia who walks out of a doctor's consulting room, for example, might be understood as refusing assessment or treatment, while in fact there could be many other reasons for their behaviour. This 'no interference' approach to autonomy may lead to relationships turning into contractual ones defined solely in terms of rights rather than relationships based on caring.

2.29 A further but related problem with some traditional accounts of autonomy is the emphasis on *rationality*: the idea that the ability to exercise autonomy and the ability to make rational decisions are one and the same thing. This can lead to the idea that respect for autonomy is either irrelevant in the context of dementia or that it is related only to what the person wanted before the onset

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<sup>91</sup> See, for example, the discussion of theories of autonomy in Beauchamp TL and Childress JF (2009) *Principles of Biomedical Ethics*, 6th Edition (New York and Oxford: Oxford University Press), pp100–2.



of dementia. As a result, too little attention is given to the individual's current wishes and feelings which, we believe, are also an expression of their autonomy.

- 2.30 We believe that these 'negative' and 'rationalistic' accounts of autonomy are not only insufficient in the context of dementia but also problematic. They are problematic because they may promote a negative view of dependence, and "the frail and infirm old who require long-term care are especially vulnerable to the pejorative meanings associated with dependence."<sup>92</sup> The concept of autonomy that we believe is relevant in dementia must give more emphasis to several additional perspectives.
- 2.31 First, enabling autonomy entails providing active support to the person with dementia so that they can be encouraged to retain and express their sense of self, rather than simply being protected from harm or interference. In order to give this support it is necessary for those providing care to try to understand what the person with dementia is feeling, wanting and experiencing. As a person's dementia becomes more severe, this will become more difficult, but if someone has limited capability to live independently or to realise their own choices, then respect for autonomy must involve others taking active steps to act as advocates and to try to promote their autonomy. Autonomy as freedom from interference completely misses the point that promoting autonomy will often require the provision of active support.
- 2.32 Secondly, in considering what it means to enhance autonomy, we must recognise that people are not isolated individuals, but are people whose identity is embedded in a network of relationships. A key aspect of who we are is founded on our relationships with those whom we love and others who are important to us. Enabling and promoting autonomy thus involves enabling and fostering relationships that are important to the person. The interests of the person with dementia, including their autonomy interests, are closely linked to the interests of those close to them, and particularly to the interests of their family and friends who are caring for them. This is an important reason why carers should receive advice and support, and this in itself can be helpful to the person with dementia as a way to enhance their autonomy.
- 2.33 Thirdly, traditional concepts of autonomy emphasise rationality at the expense of emotional factors. This can lead to an approach whereby once a person lacks (rational) capacity to make a particular decision, then respecting autonomy is assumed to relate only to the views held or decisions made by the person before losing capacity. We believe, however, that enhancing the autonomy of a person with dementia includes giving weight to their emotional responses, for example enabling them to pursue activities that they appear to enjoy even if they lack the capacity to make relevant decisions. As we discuss later in the context of personhood (see paragraphs 2.48–2.53), we also believe that people retain the ability to *value* one thing over another even after they have lost the rational ability to formulate and communicate a particular decision.
- 2.34 Several writers have provided rich accounts of autonomy emphasising and developing these additional perspectives. The terms *relational autonomy* and *actual autonomy* have been used to mark these richer accounts.<sup>93</sup> A key implication of these accounts is that the dependency of people as a result of their disease does not mean that their autonomy cannot be promoted, nor that promoting autonomy simply involves respecting the wishes and values they had before the onset of dementia. On the contrary, it means that people who have become dependent on others

<sup>92</sup> Agich GJ (2003) *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge: Cambridge University Press), p10.

<sup>93</sup> See, for example, Mackenzie C and Stoljar N (Editors) (2000) *Relational Autonomy: Feminist essays on autonomy, agency and the social self* (New York: Oxford University Press); Agich GJ (2003) *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge: Cambridge University Press).

through the development of dementia may need support from those who care for them to help them retain their autonomy, and with it their sense of self.

### Well-being

- 2.35 We have argued, on grounds of respecting autonomy, that it is important to pay close attention to the expressed desires and feelings of a person with dementia. Even if our account of autonomy is rejected, however, in favour of an account that sees rationality as so central that a person with moderate or severe dementia would be considered as incapable of expressing autonomous desires, it would still be important to pay close attention to these desires and feelings, and to do everything possible to help the person achieve their desired goals. This is on the grounds of *well-being*. A person with dementia clearly has an interest in being helped to maximise their well-being, an important aspect of which will be related to the satisfaction of their desires and preferences.
- 2.36 Several different approaches to well-being have been taken by philosophers. In the context of this Report we wish to highlight two approaches that we believe are relevant to people with dementia. The first approach focuses on a person's moment-to-moment experiences. At any one time we experience a certain level of happiness or sadness, of pleasure or pain. Maximising well-being, on this approach, would require maximising the overall sum of positive experiences, where this overall sum is made up of balancing the degrees and duration of positive experiences against the degrees and duration of negative experiences.<sup>94</sup> We believe that this is an important component of well-being and that a person with dementia has a strong interest in having positive experiences such as contentment or pleasure, on a moment-to-moment and day-to-day level.
- 2.37 The second approach to well-being is what has been called the 'objective list' theory. According to this approach, a person's well-being is not only determined by their overall happiness: it is also affected by things that are objectively good or bad independently of their influence upon happiness.<sup>95</sup> Most objective list theories will include autonomy as something that makes life go well. So on this view, the richer conceptions of autonomy that we have discussed above also contribute to a person's well-being. In the context of dementia, an important example of what contributes to objective well-being, and which is related to autonomy, is a person's level of cognitive dysfunction. It is our view that a person's well-being is negatively affected by such dysfunction, so that reduced cognitive functioning, for example as a result of sedative medication, constitutes a reduction in a person's overall well-being. Equally, a slowing down in a person's deterioration in cognitive functioning (for example owing to treatment) may prevent further deterioration of that person's well-being.
- 2.38 In considering overall well-being, therefore, both moment-to-moment experiences and cognitive dysfunction are important. A treatment that reduced distress but also increased cognitive impairment would either reduce or increase well-being depending on the balance between the effects, and both effects should be taken into account in coming to a judgment. Similarly, a treatment that reduced the deterioration in cognitive functioning, even if the person remained more distressed because of greater insight into their condition, *might* be justified on the grounds that it contributed to overall well-being. Again our view is that both effects are relevant in coming to a decision, and that the strength of each effect should be closely considered when determining whether or not the treatment would enhance the person's overall well-being.
- 2.39 One important implication of this is that the moment-to-moment experiences (of pleasure and happiness or pain and unhappiness) are important even if no memory of that moment's experience is retained. Moreover, the level of positive experience is likely to be dependent on the details of

<sup>94</sup> See, for example, Griffin J (1986) *Well-being: Its meaning, measurement and moral importance* (Oxford: Clarendon Press).

<sup>95</sup> For an example of an 'objective list' theory see John Finnis (1980) *Natural Law and Human Rights* (Oxford: Oxford University Press).

the person's life and the details of care. This is one reason why in Chapter 3 we will emphasise the importance of paying attention to the details of care and their impact on what the person is experiencing. Indeed, such concern for the ordinary and day-to-day experience is also relevant to autonomy, which can be promoted by enabling the person with dementia to make choices in the apparently small things in life – when to have a cup of tea, for example. Both autonomy and well-being might also be enhanced through enabling people with dementia to engage in productive or meaningful activities. As one of our peer reviewers put it, even “people with profound disabilities are often still able to make simple things which they can appreciate are of value to others.”

### ***The interests of carers***

- 2.40 Unpaid carers (family, friends and neighbours) provide most of the care for people with dementia, often motivated and sustained by bonds of love. Their interests are important for two reasons. First, carers are people in their own right, with the same strong claim as people with dementia to have their interests considered. In their role as carers they may face stresses and difficulties, and they may often feel that their own interests have become subordinate to those for whom they provide care. Both professionals and society more generally have duties to try to support carers, both in their caring role and as people with their own independent existence and interests. Secondly, the autonomy and well-being of the person with dementia are closely linked in with their relationships with those close to them (see paragraph 2.32).<sup>96</sup> Support which promotes the interests of carers may also, therefore, act to promote the well-being and autonomy of the person with dementia.
- 2.41 For both these reasons, support to carers of people with dementia is a crucial part of the services that should be provided in dementia care, and the interests of carers, as individuals, should be considered when difficult ethical decisions involving conflicting interests need to be made.

### ***The interests of professionals and care workers***

- 2.42 A key duty of care workers and professionals is to promote the interests of the person with dementia. This work is demanding and, as with carers, the ability of such professionals and care workers to carry out this work effectively will be enhanced by their receiving proper support themselves. This has implications for the conditions under which they work: the status of, and remuneration for, their work; the work environment, including staffing levels; the way in which they are themselves treated by their employers; and the ongoing education and mentoring that they receive.

## **Component 5: Solidarity**

**“...when men and women seem by one consent to open their shut-up hearts freely, and to think of people below them as if they really were fellow-passengers to the grave, and not another race of creatures bound on other journeys.” Charles Dickens, *A Christmas Carol***

- 2.43 Solidarity is the idea that we are all ‘fellow-travellers’ and that we have duties to support and help each other and in particular those who cannot readily support themselves. Within a society or country solidarity often comes to the fore at times of stress such as war or natural disaster. The high prevalence of dementia, and the fact that we all face a significant risk of developing dementia as we get older, might enable us to develop a particular sense of solidarity with each other in the context of dementia and dementia care.

<sup>96</sup> Hughes JC, Hope T, Reader S and Rice D (2002) Dementia and ethics: the views of informal carers *Journal of the Royal Society of Medicine* 95: 242–6.

- 2.44 The concept of solidarity underpins the duty of individuals and of society to support those with dementia and their carers. It reinforces the responsibility of all of us to try to help research and to act to de-stigmatise dementia. Solidarity is relevant also to individual relationships: personal solidarity, in the form of love, loyalty and compassion, is the basis and motivation for giving care to one's partner, parent or friend. We suggest, therefore, that, under solidarity, society has a twofold obligation to provide resources and support to people with dementia and their carers: first as part of our obligations to help those who cannot readily support themselves; and secondly to enable carers to maintain their personal solidarity with the person for whom they are caring. Lack of professional support may put carers under extreme pressure. They suffer exhaustion, lacking time or energy for sustaining an affectionate and supportive caring relationship. Likewise, a failure to show solidarity towards care workers, in the form of appropriate support and recognition, can affect their ability to develop and sustain supportive relationships with the people for whom they care.
- 2.45 When considering the idea of solidarity, those receiving care and support should not be seen simply as people with particular rights or as victims of disease or disability, but rather as citizens with both their own needs and a societal role. People with dementia may need assistance in order to be empowered and given a voice, but they should also be included as citizens with their own views on how solidarity should be practised, and with their own contribution to make.<sup>97</sup>
- 2.46 Justice, which is at the root of our notion of solidarity, is often defined as a fair distribution of benefits and burdens, particularly in connection with misfortunes for which we cannot be held personally responsible. Given the potential vulnerability of people with dementia, it is particularly important that the allocation of resources results in a supportive environment in dementia care. This is in part an issue of appropriate resources and practical support, but also requires both carers and care workers to be recognised and valued as people who have an important expertise and role in society.
- 2.47 A fair distribution of benefits and burdens should promote and sustain solidarity, realised as a willingness to support the person with dementia throughout the course of their dementia and to help them in maintaining their autonomy as much as possible.

### Component 6: Recognising personhood

- 2.48 Some philosophers have argued that a person with severe dementia ('person B') may quite literally be a different person – have a different identity – from the person before the dementia ('person A'). This position has its origins in the view that to be able to identify oneself as the same person over time requires memory.<sup>98</sup> There has been considerable philosophical debate over this issue.<sup>99</sup> Some carers also consider the person with dementia as a 'different person' from before, although this is not often meant literally but instead refers to major and distressing changes in mood and behaviour resulting from the dementia.

<sup>97</sup> See also: Houtepen R and ter Meulen RHJ (2000) The expectations of solidarity: matters of justice, responsibility and identity in the reconstruction of the health care system *Health Care Analysis* 8: 355–76.

<sup>98</sup> Locke J (1700) *An Essay Concerning Human Understanding*, Woolhouse R (Editor) (London: Penguin Classics 1997), p302: "since consciousness always accompanies thinking, and 'tis that, that makes every one to be, what he calls self; and thereby distinguishes himself from all other thinking things; in this alone consists *personal identity*, i.e. the sameness of a rational being; and as far as this consciousness can be extended backwards to any past action or thought, so far reaches the identity of that person; it is the same *self* now it was then; and 'tis by the same *self* with this present one that now reflects on it, that that action was done."

<sup>99</sup> See, for example, Buchanan A (1988) Advance directives and the personal identity problem *Philosophy and Public Affairs* 17: 277–302; Hope T (1994) Personal identity and psychiatric illness, in *Philosophy, Psychology and Psychiatry*, Griffiths AP (Editor) (Cambridge: Cambridge University Press), pp131–43; Dresser R (1995) Dworkin on dementia: elegant theory, questionable policy *Hastings Center Report* 25(6): 32–8; Hughes JC, Louw SJ and Sabat SR (Editors) (2006) *Dementia: Mind, meaning, and the person* (Oxford: Oxford University Press).

- 2.49 The view that a person literally changes identity has profound implications. One implication is that an advance decision made by person A (the person with capacity before the dementia), and person A's values, are irrelevant in making decisions about person B. A second implication is that person A has ceased to exist and this raises the question of what to do with his or her property. A third implication is that the relatives and friends of person A have no long-standing relationship or ties with, and few duties towards, person B. Many philosophers reject this view and argue for the common-sense position that even if the person's mood, behaviour and memory change profoundly, the person with severe dementia is still the same person as before the onset of dementia. According to this latter view, personal identity depends on other (additional) factors, for example on bodily identity,<sup>100</sup> and on interpersonal identity established through relationships with others.<sup>101</sup>
- 2.50 The various positions on these issues reflect current philosophical controversies which are partly metaphysical in nature. We do not aim to settle these controversies, but simply to offer practical and policy guidance regarding ethical issues arising in the care of people with dementia. From this perspective we believe that the position that a person retains their identity throughout the course of dementia (even though they may behave in profoundly different ways) provides a better guide to policy and practice. The facts of bodily identity, and social connections, in particular, provide important grounds for considering a person as the same person throughout the full course of the illness. Some implications of this position are: that the views and values of the person before the onset of dementia may be relevant in making decisions; that the resources that the person has accumulated during their life may be used for their benefit; and that family and friends may retain responsibilities, and also expectations, that are normally assumed. This position also avoids some of the major practical problems that are associated with the alternative, particularly those associated with considering that one person has died (the person before the onset of severe dementia) and that a new person has come into existence – a person without any social connections. In short, although mood and behaviour may be profoundly affected by dementia, personal identity is not: the individual remains the same person throughout the process of dementia.
- 2.51 A further view, which we also reject, is that in severe dementia the individual may not merely have a different identity but may cease to be a 'person' at all. This view is based on the idea that in order to be a 'person', a certain level of cognitive functioning is required, and that in severe dementia such cognitive functioning may fall below the required level. The practical implications of this view might include: that the individual with severe dementia should not enjoy the protections of the law that are given to 'persons'; that the individual with dementia does not have any interests, or none beyond those of other (non-human) living creatures; that those close to the individual with dementia no longer have any interests or duties towards them; and perhaps that the views and values of the individual before the onset of dementia are no longer relevant in making decisions about their care.
- 2.52 This view – that in severe dementia an individual may cease to be a person at all – is subject to as much philosophical controversy, as is the issue of personal identity. There are two principal reasons why we reject this view. The first is uncertainty over what an individual with severe dementia is experiencing, and what is going on in the individual's mind. It has been argued that we should think of people with dementia as 'valuers': people capable of valuing.<sup>102</sup> Most of the time the

<sup>100</sup> Matthews E (2006) Dementia and the identity of the person, in *Dementia: Mind, meaning, and the person*, Hughes JC, Louw SJ and Sabat SR (Editors) (Oxford: Oxford University Press), pp163–77.

<sup>101</sup> See, for example, Agich GJ (2003) *Dependence and Autonomy in Old Age: An ethical framework for long-term care* (Cambridge: Cambridge University Press); Kitwood T (1997) *Dementia Reconsidered: The person comes first* (Buckingham, UK: Open University Press), p8.

<sup>102</sup> Jaworska A (1999) Respecting the margins of agency: Alzheimer's patients and the capacity to value *Philosophy and Public Affairs* 28(2): 105–38. This point was also endorsed by people with first-hand experience of dementia at the Working Party's fact-finding meeting on 10 July 2008.

person with dementia will be able to convey their values, and the ability to value may persist, even into severe dementia, when the person's inclinations can still be shown by facial features, by gestures and by the expression of emotions.<sup>103</sup> Examples cited by individual Working Party members included powerful responses to music or strong emotional attachments to pets demonstrated by people with severe dementia, even where such attachments had not been particularly important to them in the past.

- 2.53 Secondly, the view that someone with profound dementia has little value and no interests is based on seeing personhood exclusively in terms of cognitive abilities. However, emotional and spiritual aspects of a person's life are also relevant to personhood, and the various perspectives discussed above in the context of personal identity may also be relevant to personhood itself. Religious approaches to the nature of 'personhood' emphasise the belief that humans do not have to prove their worth as persons, and that it is our capacity to 'be' rather than our capacity to 'do' that gives us value as a person.<sup>104</sup> Such a belief is shared by many non-religious thinkers, who argue for the equality of human worth, regardless of the abilities or merits of any particular individual.<sup>105</sup> If we see people as both situated in a network of relationships and 'embodied' in their own physical presence, then an individual even with severe dementia remains the same, equally valuable, person, throughout the duration of their entire illness.<sup>106</sup>

### A note on dignity

- 2.54 The idea of *human dignity*, and of treating people with *dignity*, is widely used in discussions of ethics and health care, and has been used in many ways, leading some philosophers to consider that it is too vague a concept to be useful.<sup>107</sup> Some, while seeing value in the idea, nevertheless caution that "the concept of human dignity ... is something of a loose cannon ... it can oversimplify complex questions."<sup>108</sup> One analysis of the idea of dignity distinguishes between dignity as a "constraint" and dignity as "empowerment."<sup>109</sup> Dignity may constrain, in the sense that certain actions are absolutely forbidden as being counter to human dignity. Dignity may also empower, by underpinning the ethical importance of treating a person in a way which maintains and upholds their value as a human being.
- 2.55 We believe that it is the idea of treating a person with dignity, in the sense of 'dignity as empowerment', that can be particularly helpful in the setting of dementia care. In many situations it is immediately apparent what would be meant by treating a person with dignity and what it would mean to treat a person in an undignified manner. For example, it would be wrong, in the setting of a care home, to leave a woman with dementia in the sitting room only partially clothed. It would not be right, in our opinion, to defend such behaviour by saying that the person was unaware that she was only partially dressed and that therefore she was not harmed by it. One way of expressing what is wrong with treating a person in this way is to say that it does not affirm or respect her dignity, that it does not reflect the way those working in the care home would themselves like to be treated. Because there is a general and widespread understanding

<sup>103</sup> Dekkers WJM (2004) Autonomy and the lived body in cases of severe dementia, in *Ethical Foundations of Palliative Care for Alzheimer Disease*, Purtilo RB and ten Have HAMJ (Editors) (Baltimore and London: Johns Hopkins University Press), pp115–30.

<sup>104</sup> See, for example, MacKinlay E (Editor) (2008) *Ageing, Disability and Spirituality: Addressing the challenge of disability in later life* (London and Philadelphia: Jessica Kingsley), pp11–21.

<sup>105</sup> See, for example, Vlastos G (1969) Human worth, merit, and equality, in *Moral Concepts*, Feinberg J (Editor) (London: Oxford University Press), pp141–52.

<sup>106</sup> Aquilina C and Hughes JC (2006) The return of the living dead: agency lost and found?, in *Dementia: Mind, meaning, and the person* Hughes JC, Louw SJ and Sabat SR (Editors) (Oxford: Oxford University Press), pp143–61.

<sup>107</sup> For discussion of this see Ashcroft R (2005) Making sense of dignity *Journal of Medical Ethics* 31: 679–82.

<sup>108</sup> Beylveled D and Brownsword R (1998) Human dignity, human rights, and human genetics *Modern Law Review* 61: 661–81 at 662.

<sup>109</sup> Beylveled D and Brownsword R (2001) *Human Dignity in Bioethics and Biolaw* (Oxford: Oxford University Press).

of what respects dignity in this sense, it is useful for those caring for people with dementia, and for those involved in setting standards in dementia care, to think about how the dignity of people with dementia can best be respected and what actions and attitudes may undermine it. The concept of dignity is valuable, therefore, in guiding attitudes and approaches to the care of people with dementia. It emphasises the importance of attending to the details of care and a concern for what the person and their relatives might be experiencing.

- 2.56 The concept of dignity does not stand alone, however, and its importance and value can be derived, we believe, from the ethical framework that we have set out in this Chapter. On the basis of our analysis there are at least three reasons why treating a person in an undignified way may be morally wrong. First, the person might feel uncomfortable or demeaned, even if she cannot express what she wants, or the fact that she is upset. Thus, treating a person in this way may be contrary to the promotion both of her current autonomy and her well-being. Secondly, even if it were true, in the above example, that the person with dementia was unaware of, and unaffected by, the way she is left in the sitting room, this is likely to be against her past autonomy interests – her interests in having the views and values that she had previously held respected. Thirdly, treating a person in this way risks treating her as an ‘object’ rather than as a person; treating with dignity is a key part of showing respect for the personhood of the individual, recognising her value as a person, equal to anyone without dementia.

## Conclusions

- 2.57 We summarise in Box 2.1 above the six components that we have outlined in this Chapter, and which we believe provide a helpful framework for tackling the ethical problems which arise continually in dementia. In the remaining Chapters of this Report, we will consider how this framework may be of assistance in a number of different areas where ethical difficulties arise: in general approaches to care and support; in the relationships between people with dementia and others in society; when making health and welfare decisions; in aspects of care which pose particular challenges; in the consideration of carers’ own interests; and in research.