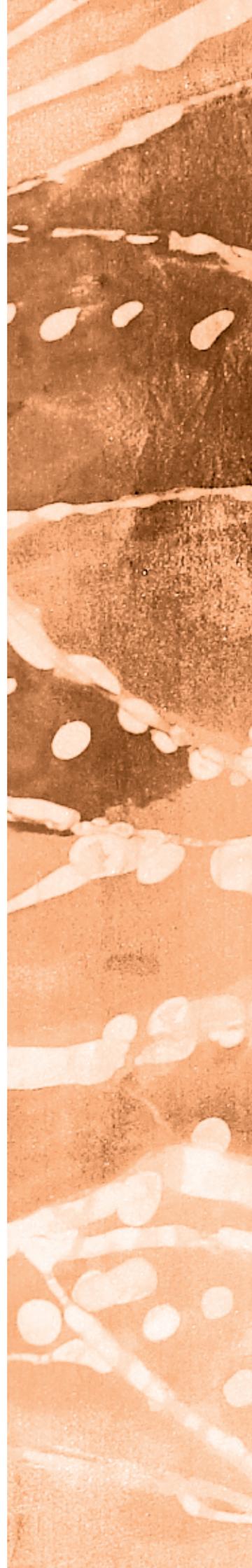


Chapter 5

Making decisions



Chapter 5 – Making decisions

Introduction

- 5.1 It is a long-established legal principle in the United Kingdom that adults who are capable of doing so are entitled to make their own decisions about their health care. In particular, they are entitled to refuse any medical investigation or treatment, even life-saving treatment, and to make choices between different treatment options where these are available. This legal principle applies equally to people with dementia, as long as they retain the capacity to make the decision in question.²⁵⁷
- 5.2 The same general principle also applies to many areas of personal welfare: for example, adults capable of doing so are entitled to decide where they live, what they eat, and how they spend their time, whatever others think of their choices. In making both health and welfare decisions, an adult with legal capacity is thus entitled to make decisions that might be widely perceived as foolish or risky. However, this principle is not absolute: a person does not have the right to demand medical treatments that clinicians regard as inappropriate to the condition, and some treatments may be too expensive for the state to provide. There are also many limitations, based on concern for others, on ideas of what is publicly acceptable, and indeed on what we can afford, that are placed on our ability to live our lives in exactly the way we wish.
- 5.3 The ethical basis for the right of adults with capacity to refuse interventions, in both the health care and personal welfare field, is widely seen as respect for autonomy in the sense of respect for self-governance: the right to manage and control one's own life. Such an approach tends to emphasise the *individualistic* aspects of autonomy, seeing the person making the decision essentially in isolation, rather than as part of a family or social group where others may have an important part to play in supporting the person making the decision and whose own interests may be affected by that decision. Respect for autonomy in this sense is also closely bound up with the value placed on a person's *rational* abilities, in particular the ability to weigh up options, make a decision, and then take responsibility for the outcome of that decision. Indeed, most accounts of autonomy are firmly founded on the assumption that in order to be an autonomous being, or exercise autonomy, a person must have capacity for rational thought.²⁵⁸
- 5.4 In Chapter 2, however, we proposed a richer concept of autonomy, arguing that it should not be equated simply with the individual's ability to make and communicate rational decisions. Rather, we suggested that a person's autonomy is found also in how they express their sense of self, in their relationships with those important to them, and in their values and preferences. This richer concept, we argued, is more appropriate to people with dementia than the highly individualistic account of autonomy. In order to promote autonomy in this broader sense, we need to support the person with dementia in maintaining their sense of self and expressing their values, even where their rational decision-making abilities have become impaired: for example through enabling and fostering relationships that are important to the person and recognising that people may need assistance in making and exercising their autonomous choices. In this way, it may be possible to help a person with even quite severe cognitive impairment make choices that reflect their values and wishes. In addition, those close to the person may also have an important stake in a particular decision. Compromises reflecting the interests of all involved are a normal part of family life, and respect for autonomy does not mean that one person's interests should always be prioritised over others. This is not simply about balancing one person's autonomy against another's. In the context

²⁵⁷ We do not cover here those exceptional cases where people with dementia can be subject to the provisions of the various mental health statutes in the UK, where the decisions even of people with capacity may, in certain circumstances, be overridden.

²⁵⁸ See, for example, Beauchamp TL and Childress JF (2009) *Principles of Biomedical Ethics*, 6th Edition (New York and Oxford: Oxford University Press), p101.

of close relationships, what each person wants usually involves taking into account what the others also want.

- 5.5 We fully endorse the principle that a person with capacity has the right to make their own health and welfare decisions, within the general constraints outlined in paragraph 5.2. The question of capacity, however, is not always straightforward in the context of dementia, and a person with dementia may need care and support from others in order to express and exercise their autonomous wishes. If the person is refusing care or treatment that seems clearly in his or her best interests, and if the person has the capacity to make that decision, then it is important, in respecting the decision, to ensure that the situation is regularly re-assessed. Similarly, when a person has been assessed as lacking legal capacity for a particular decision, it is still crucial to give full consideration to their current values, wishes and feelings.

Legal approaches throughout Europe

- 5.6 A survey carried out in 2005 by Alzheimer Europe provided a snapshot of legal approaches to consent, capacity and incapacity in over 20 (primarily Western) European countries.²⁵⁹ The legal systems in all the countries surveyed recognised the right of an individual with capacity to give or withhold consent to treatment,²⁶⁰ and all were based on the 'presumption of capacity': that is, a person is assumed to have capacity to make their own decisions unless the opposite has been demonstrated. Most countries had explicit provision for some form of substitute decision making, primarily through relatives or court-appointed guardians, and in some countries the legislation allowed for a degree of flexibility in these systems, recognising that capacity may fluctuate or decline over time. A minority of countries have also passed legislation to permit a person to nominate their own decision maker, should they lose capacity in the future, rather than relying on a court decision.
- 5.7 While comparisons between legal systems must be treated with some caution, since the detail and practical effect of legislation inevitably varies from country to country, there is clearly a broad consensus across Western Europe, and also in North America,²⁶¹ that those with dementia have a right to make their own decisions while they retain the capacity to do so, but that some form of substitute decision-making system is also necessary. Thus, although the rest of this Chapter focuses primarily on the legal systems within the United Kingdom, its conclusions may still be of relevance to many other jurisdictions.

The legal framework in the UK: the mental capacity Acts

- 5.8 The Mental Capacity Act 2005 provides a legal framework for decision making in England and Wales in cases where individuals do not have the capacity to make specific decisions for themselves. The Act was based on the pre-existing common law principle that those who lack capacity to make a particular decision should be treated in their 'best interests', and was developed through a process of careful consideration and review by both the Law Commission and Parliament. The equivalent statute in Scotland is the Adults with Incapacity (Scotland) Act 2000, which had a similar process of gestation to the English/Welsh Act. There is, as yet, no Act governing this area in Northern Ireland, where the common law principle of 'best interests' still applies without a statutory framework.²⁶²

²⁵⁹ Alzheimer Europe (2005) *Comparative Analysis of Legislation in Europe Relating to the Rights of People with Dementia: Final report* (Luxembourg: Alzheimer Europe).

²⁶⁰ Subject, of course, to those exceptions where compulsory treatment is given under mental health legislation.

²⁶¹ Alzheimer's Association (2005) *Legal Plans: Assisting the person with dementia in planning for the future* (Chicago: Alzheimer's Association).

²⁶² Guidance issued by the British Medical Association suggests that where an individual lacks capacity, treatment decisions in Northern Ireland will be the responsibility of the treating clinician, on the basis of the person's best interests: BMA (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment* (Oxford: Blackwell Publishing), pp69–70. This is based on the House of Lords case *Re F (mental patient: sterilisation)* [1989] 2 All ER 545.

Legislation for Northern Ireland in this area has, however, been promised by 2011.²⁶³ Both the English/Welsh and Scottish Acts include a set of 'guiding principles' (see Box 5.1 below). These emphasise the underlying ethos of each Act that a person's ability to make their own decisions should be promoted and supported as much as it is possible to do so. Both Acts also include provision for statutory Codes of Practice in which much more detailed guidance may be provided.²⁶⁴

Box 5.1: Guiding principles of the mental capacity Acts

Mental Capacity Act (England and Wales)

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

s1 Mental Capacity Act 2005

Adults with Incapacity (Scotland) Act

- **Benefit:** There shall be no intervention in the affairs of an adult who lacks capacity unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention.
- **Minimum intervention:** Any such intervention must be the least restrictive option in relation to the freedom of the adult.
- **Take account of adult's wishes and feelings:** When determining whether an intervention is to be made, account must be taken of the present and past wishes and feelings of the adult.
- **Consult others:** The views of other relevant people must be taken into account.
- **Encourage exercise of residual capacity:** The adult must be encouraged to exercise whatever skills he or she has, and to develop new skills.

s1 Adults with Incapacity (Scotland) Act 2000, as summarised in Scottish Government (2007) *Adults with Incapacity (Scotland) Act Code of Practice: For practitioners authorised to carry out medical treatment or research under part 5 of the Act*, 2nd Edition, part 1, available at: www.sehd.scot.nhs.uk/mels/CEL2008_11.pdf.

Proposed principles in Northern Ireland.

- **Autonomy:** The right of the individual to decide and act on his or her own decisions.
- **Justice:** Applying the law fairly and equally.
- **Benefit:** Promoting the health, welfare and safety of the person, whilst having regard to the safety of others.
- **Least harm:** Acting in a way that minimises the likelihood of harm to the person.

Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 3.1.

5.9 This Chapter will first provide an overview of the current law in the UK governing incapacity and decision making. It will then analyse some of the key ethical difficulties which arise when a person is no longer able to make a particular decision on their own because of dementia, and explore whether, in the context of the ethical framework set out in Chapter 2, further guidance within the current legal framework might be helpful in supporting those responsible for making such decisions.

²⁶³ Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 1.4.

²⁶⁴ Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (London: The Stationery Office); Scottish Government (2007) *Adults with Incapacity (Scotland) Act Code of Practice: For practitioners authorised to carry out medical treatment or research under part 5 of the Act*, 2nd Edition; six further Codes of Practice issued under the Adults with Incapacity (Scotland) Act, covering different aspects of the Act, are available at www.scotland.gov.uk/Topics/Justice/law/awi/010408awiwebpubs/cop.

Overview of the legal provisions

Capacity

- 5.10 Although there are differences in detail between the English/Welsh and Scottish Acts and the proposals in Northern Ireland, in each case the underlying approach to the concept of incapacity is broadly the same. In all three jurisdictions, the starting point is that a person will be presumed to have capacity to make a particular decision unless the contrary is demonstrated. A person will be held to lack legal capacity in connection with a particular decision only if they are incapable of making, understanding or communicating that decision. Capacity should always be ‘decision-specific’: an individual may lack capacity to make one decision but retain sufficient capacity to make another decision. It may also fluctuate: a person may lack the capacity to make a particular decision in the evening when they are tired, for example, but be quite capable of making the same decision in the morning. Both the English/Welsh and Scottish Acts also specify that all reasonable attempts must be made to help people make their own decisions, and the Northern Ireland proposals similarly state that the “new legislation should support people to make their own decisions.”²⁶⁵
- 5.11 These approaches to capacity are particularly important in connection with dementia, where capacity may fluctuate significantly, and where capacity may be retained for some decisions long after it is lost for others. It is to be hoped, therefore, that anecdotal evidence of professionals and care workers mistakenly assuming that incapacity is a general condition, rather than being decision-specific, will quickly become a thing of the past.

Best interests and benefit

- 5.12 Although the underlying approach to lack of capacity is similar across the UK, the statutory provisions in England/Wales and in Scotland do differ both in terms of language and in the structures and systems used to protect and promote the welfare of those who lack legal capacity.²⁶⁶ In England and Wales, if an individual lacks capacity to make a particular decision (and has not made a valid and applicable advance decision as described in paragraph 5.15), then the Mental Capacity Act specifies that others, such as family, friends, or health and social care professionals, must act in the individual’s ‘best interests.’
- 5.13 There is no simple definition of best interests in the Act, but includes factors that should be considered when judging best interests, including the person’s “past and present wishes and feelings”, and “the beliefs and values that would be likely to influence his decision if he had capacity” (see Box 5.2 below). Nor does the Act spell out *who* should take particular decisions: rather it states that people act lawfully if they reasonably believe that they are acting in the incapacitated person’s best interests.
- 5.14 In Scotland, the Adults with Incapacity (Scotland) Act does not use the language of ‘best interests’, and instead requires that any intervention must *benefit* the adult, in a way that could not be achieved without the intervention. When deciding whether an intervention is justified, the Scottish Act suggests that account should be taken of “the present and past wishes and feelings of the adult” and also of the views of those closely involved with the individual.

²⁶⁵ Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 4.1.

²⁶⁶ The Northern Ireland legislative proposals published in January 2009 do not go into this degree of detail but simply note that the proposed Mental Capacity Bill “will provide detail on what substitute decision makers will need to take account of when acting on behalf of an individual with impaired capacity” – see Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 4.3.

Box 5.2: Best interests and benefit**'Best interests' in England and Wales**

Factors to take into account when determining a person's best interests include:

- the person's past and present wishes and feelings (in particular any relevant written statements made before loss of capacity);
- the beliefs and values that would be likely to influence the person's decision if they had capacity;
- other factors they would be likely to consider if they were able to do so; and
- where practical and appropriate, the views of a number of others concerned with the person's welfare as to what action would be in the person's best interests.

The person who lacks capacity must be encouraged to participate as fully as possible in any decision taken on their behalf.

ss4(4), 4(6) and 4(7) Mental Capacity Act 2005.

'Benefit' in Scotland

Factors to be taken into account when determining whether an intervention might benefit an adult include:

- the person's past and present wishes and feelings; and
- the views of a number of others concerned with the person's welfare, in so far as it is reasonable and practicable to obtain them.

The person who lacks capacity must be encouraged to participate as fully as possible in any decision taken on their behalf.

s1(4) Adults with Incapacity (Scotland) Act 2000.

Advance decisions

5.15 The Mental Capacity Act also makes specific provision for people in England and Wales to make 'advance decisions' to refuse treatment. Such decisions are legally binding on professionals if they are valid and applicable to the treatment in question. They will not, however, be binding if they have been invalidated in some way, for example if people change their mind while they still have capacity, or if they do "anything else clearly inconsistent with the advance decision remaining [their] fixed decision."²⁶⁷ The Northern Ireland proposals also include provision for advance decisions to refuse treatment.²⁶⁸ The Adults with Incapacity (Scotland) Act does not make any reference to advance refusals of treatment, although the Scottish Code of Practice notes that they are "potentially binding."²⁶⁹ Advance decisions are discussed further in paragraphs 5.33–5.49.

Proxy decision making

5.16 Both mental capacity Acts also make provision for 'proxy' decision making. People who still have the capacity to do so may nominate someone, typically a spouse or close relative, to be a 'welfare attorney' to make health or welfare decisions for them in the future.²⁷⁰ In England and Wales, the legal instrument used to nominate a 'welfare attorney' is called a lasting power of attorney (LPA) and the attorney may also be known as the 'donee' of the LPA.²⁷¹ The person retains the right to make their own decisions as long as they are capable of doing so: the welfare attorney only steps in if the person lacks the capacity to make a specific decision. Individuals may choose how much power to give their welfare attorneys: they may choose to restrict the areas in which the attorneys can make decisions, or may specify that the attorneys can take any health or welfare decision on their behalf. The Mental Capacity Act explicitly states that the power granted to an attorney may include the power to refuse life-sustaining treatment, while the Adults with Incapacity (Scotland) Act is silent on this point. While there is currently no equivalent provision in Northern Ireland, the

²⁶⁷ s25(2) Mental Capacity Act 2005.

²⁶⁸ Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 5.1.

²⁶⁹ Scottish Government (2007) *Adults with Incapacity (Scotland) Act 2000 Code of Practice: For persons authorised to carry out medical treatment or research under Part 5 of the Act* (Edinburgh: The Scottish Government), paragraph 2.30.

²⁷⁰ There is, as yet, no equivalent provision in Northern Ireland.

²⁷¹ A Lasting Power of Attorney may also be used, separately, to nominate an attorney to make decisions about a person's property and affairs. The rules governing 'welfare' attorneys and 'property and affairs' attorneys differ, and this Chapter is concerned only with the former.

legislative proposals include the intention to create a lasting power of attorney.²⁷² We discuss proxy decision making further at paragraphs 5.53–5.63.

Review of the implementation of the Mental Capacity Act

5.17 In October 2008, the Office of the Public Guardian (an executive agency of the Ministry of Justice) published a consultation paper seeking views on some of the bureaucratic aspects of the Mental Capacity Act, such as the complexity of the forms used and the level of fees charged.²⁷³ This consultation paper constituted the first stage of a wider review of the implementation of the Act over the following 18 months. Other areas that will be addressed in the future will include the impact of the Act, whether the Code of Practice and other guidance and information on the Act is sufficient, and whether the Office of the Public Guardian is carrying out its supervisory functions appropriately.

Difficulties around borderline and variable capacity

“Perhaps the most important issue is time. People with dementia cannot be rushed into decisions and a structured, clear approach by a person or persons can go a long way towards bringing about a resolution where the affected person is expressing wishes that are not in their family’s best interests.” *National Prion Clinic, consultation respondent*

“We have noticed that it is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions (which will have great impact on their future well-being), thereby ‘de-humanising’ them.” *Christian Council on Ageing; Faith in Elderly People, Leeds, consultation respondents*

5.18 It is well established that the capacity of an individual with dementia may vary considerably in relation to the same decision: people often have ‘good’ and ‘bad’ times of the day, and cognitive abilities may also be affected by a range of factors unconnected with their dementia, such as the presence of other illnesses or their current levels of emotional well-being. The Mental Capacity Act Code of Practice highlights the need to choose the best time and best circumstances for assessing a person’s capacity,²⁷⁴ and the Scottish Code of Practice for medical practitioners emphasises that if a decision can be deferred until a time when a person is likely to have sufficient capacity to take it, then it should be.²⁷⁵ This approach was reiterated by a number of respondents to our consultation. It is also important to note that the way a person is approached and spoken to may in itself affect their capacity or apparent capacity to make a decision: it is increasingly recognised how the use of an infantilising manner or language – ‘elderspeak’ – actively disempowers older people from involvement in their own care.²⁷⁶

5.19 However, the assessment of a person’s capacity can never be an exact science (particularly where there are significant communication difficulties), and it is still quite possible that different professionals, acting in full knowledge of the Acts, may come to different conclusions as to whether the person

²⁷² Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 5.1.

²⁷³ Office of the Public Guardian (2008) *Reviewing the Mental Capacity Act 2005: Forms, supervision and fees – consultation paper CP26/08* (London: Ministry of Justice).

²⁷⁴ Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (London: The Stationery Office), paragraph 4.36.

²⁷⁵ Scottish Government (2007) *Adults with Incapacity (Scotland) Act 2000 Code of Practice: For persons authorised to carry out medical treatment or research under Part 5 of the Act* (Edinburgh: The Scottish Government), paragraph 1.16.

²⁷⁶ See, for example, University of Kansas Medical Center News Release (2008) *Respectful adult communication improves quality of care in Alzheimer’s patients*, 28 July, available at: www2.ku.edu/~kugeron/news/; British Medical Association (2009) *The Ethics of Caring for Older People*, 2nd Edition (Chichester: Wiley-Blackwell), pp20–1.

has sufficient understanding to make a particular decision at a particular time. The implications for the individuals concerned are potentially very significant: if they are assessed as having capacity they will be free to choose their own course of action (even if regarded by others as highly risky), whereas if they are assessed as lacking capacity their wishes may be overruled by others in the hope of protecting their best interests.

- 5.20 Under the current law, a person either has, or does not have, the capacity to make a particular decision at a particular point in time, and it is difficult to see how else a law could be framed without creating “an impossibly woolly situation.”²⁷⁷ However, as the examples above suggest, this approach is itself problematic with respect to important decisions, particularly in the earlier stages of dementia, where very different outcomes may arise from marginal differences in capacity (or indeed in opinions about capacity).
- 5.21 One possible approach that has been suggested for avoiding, or at least reducing, the problems inherent in borderline capacity is greater emphasis around joint decision making with trusted family members. It is suggested that such *joint* decision making might help bridge the gap between the time when a person with dementia is fully able to make his or her own decisions, and the time when some kind of formal proxy decision making becomes necessary on a regular basis.²⁷⁸ Indeed, such an approach is implicit in the requirement set out in both the Mental Capacity Act and the Adults with Incapacity (Scotland) Act that all practicable steps must be taken to help an individual make a decision before concluding that he or she lacks capacity.²⁷⁹
- 5.22 Clearly, it would be important that such an arrangement did not undermine the use of a welfare power of attorney where dementia had progressed to the point that this became necessary. Moreover, the appropriateness of family involvement would always depend heavily on existing family relationships: some people with dementia will have family members whom they trust, and whom professionals also feel able to trust, and others will not. The extent to which the person with dementia is willing to share their confidential clinical information with others will also vary considerably from person to person. However, professionals could facilitate such an approach for those who would welcome it, by making clear from the outset that they are willing to engage and communicate with carers and family members, and facilitate joint decision making, if that is what the person with dementia wishes. We note that such an approach is consistent with our earlier recommendation (see paragraph 3.23) that professionals should encourage people receiving a diagnosis of dementia to share that information with those close to them, on the basis that dementia, more than many other health conditions, affects whole families and not just individuals.
- 5.23 **As we discuss in Chapter 2, most people do not make ‘autonomous’ decisions in isolation: rather they come to decisions supported by those close to them and in the light of those relationships (see paragraphs 2.31–2.32). Joint decision making with trusted family or friends is one example of how our broader approach to autonomy can be realised in practice, and is potentially valuable both in meeting the legal requirement to take all practicable steps to support a person in making their own decision and in supporting the person in ‘borderline’ cases where their capacity is uncertain.**

Recommendation 4: We recommend that the Codes of Practice made under the Mental Capacity Act and the Adults with Incapacity (Scotland) Act should be amended to emphasise the importance of good communication and supportive relationships with families, so that joint decision making is encouraged wherever appropriate.

²⁷⁷ Dr Ian M. Jessiman, responding to the Working Party's consultation.

²⁷⁸ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q14; see also Molinari V, McCullough LB, Coverdale JH and Workman R (2006) Principles and practice of geriatric assent *Aging & Mental Health* 10(1): 48–54 where an “active collaboration” between health professionals and people with impaired capacity is promoted.

²⁷⁹ s1(3) Mental Capacity Act 2005; s1(5) Adults with Incapacity (Scotland) Act 2000.

Determining best interests/benefit: balancing past and present

“... if the person expressly requested things when they had capacity, then those wishes should be adhered to.” *Daphne Sharp, consultation respondent*

“Preventing someone from taking actions that make them happy now because it may not have made their old selves happy is difficult.” *European Care Group, consultation respondent*

“If his/her current wishes and values are totally at odds with the past, then it would be helpful to try to understand the change... whether it is based, for example, on a sense of insecurity, fear or as consequence of the illness e.g. disinhibited behaviour; or because the person is genuinely enjoying doing things differently.” *Alzheimer Scotland, consultation respondent*

- 5.24 Given the central role ‘best interests’ or ‘benefit’ play in legal provisions, a crucial question which must be addressed is how these terms should be understood. In Chapter 2, we identified two distinct sets of interests to be considered: on the one hand, a person’s ‘autonomy interests’, which include having the freedom to act in accordance with one’s own values, in a way that seems true to oneself; and, on the other, their ‘well-being interests’, which include both maximising day-to-day happiness and promoting aspects of the person’s life which are seen as objectively good. The legal approach to best interests in England/Wales and in Scotland includes consideration of both these sets of interests, requiring decision makers to consider both what would be ordinary good practice in clinical care and what the person in question might have chosen when they had capacity.²⁸⁰
- 5.25 When considering what kind of decision the person would have made, had they still had capacity, the English/Welsh and the Scottish Acts refer to both ‘past’ and ‘present’ wishes and feelings. In many cases there will be clear continuity between the way people with dementia approach their life now and in the past. However, situations can and do arise where an individual’s past and present views on a particular question seem to diverge sharply. In these circumstances, the Scottish Code of Practice for medical professionals suggests that “the most recently expressed view/wish made while the adult had capacity, will prevail.”²⁸¹ The English/Welsh Code of Practice is less specific, highlighting the importance of strong views in the past, particularly those set down in writing, but emphasising that these would not be the only factor to take into account when considering best interests.²⁸²

Case example: Mrs A²⁸³

Earlier in her life, Mrs A made it clear that she would not value life with dementia and if, at some point in the future, she were to develop dementia and lose capacity to make her own decisions, she would not want any medical treatment which might prolong her life. Mrs A goes on to develop dementia. She appears to be contented, spending her days happily reading random pages of a detective story, enjoying walking round the garden, drawing the same picture repeatedly, and eating her favourite food. Difficulties may arise in determining whether her past or present preferences should dominate when making critical decisions about her health care if she is not able to form or communicate her views herself: for example, whether she should be given antibiotics to treat a chest infection in circumstances where the antibiotics would be highly likely to prolong her life.

²⁸⁰ The Northern Ireland legislative proposals published in January 2009 do not go into this degree of detail but simply note that the proposed Mental Capacity Bill “will provide detail on what substitute decision makers will need to take account of when acting on behalf of an individual with impaired capacity” – see Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 4.3.

²⁸¹ Scottish Government (2007) *Adults with Incapacity (Scotland) Act 2000 Code of Practice: For persons authorised to carry out medical treatment or research under Part 5 of the Act* (Edinburgh: The Scottish Government), paragraph 2.33.

²⁸² Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (London: The Stationery Office), paragraphs 5.40–5.

²⁸³ Based on the case of ‘Margo’ as described in Firlirk AD (1991) Margo’s logo *Journal of the American Medical Association* 265(2): 201.

5.26 As the case of Mrs A demonstrates, it may not always be easy to decide what course of action is genuinely in a person's best interests. There are very strong differences of opinion among ethicists as to whether previously held opinions or current preferences should take precedence in such circumstances,²⁸⁴ and similarly conflicting views were apparent both in the responses we received from our public consultation questions on this issue,²⁸⁵ and in our public deliberative event involving members of the public with little or no prior knowledge of dementia.²⁸⁶ Indeed, it was noticeable that this was the one area of discussion at our deliberative event where no compromise was found to be possible, with participants taking clear and opposing views.

5.27 Arguments in favour of prioritising the person's *past* preferences include the following:

- The belief that such preferences are likely to be carefully thought-through, and reflect the person's whole approach to their life, what they value, and the kind of person they are or would like to be.
- The importance of permitting people to exercise control over their future (incapacitated) lives.
- The belief that the preferences of the person who no longer has capacity do not have the same status as their past preferences, because they cannot be the result of a rational decision-making process.
- The practical difficulties inherent in interpreting the preferences of people who are no longer able to communicate clearly.²⁸⁷

5.28 Arguments in favour of prioritising the person's *present* preferences include:

- The belief that a person with dementia, however cognitively impaired, has a perspective that is valid, even though it is rooted in the present moment rather than in the past.
- The belief that people with dementia remain 'valuers' and that cognitive impairment does not prevent people from holding and expressing values, if need be through gesture and facial expression.
- The concern that people should not be 'held to ransom' by their past beliefs and assumptions, especially as such attitudes may change radically when facing major life events. In the same way, people with capacity can and do change their minds throughout their lives, either because of changing perspectives or because of extra information and reassurance provided by others at the time a decision needs to be made, and do not expect to be bound by attitudes and beliefs they once held but have now discarded.
- The belief that, once the individual with dementia can no longer remember their past beliefs and wishes, they are no longer the same 'person' as they once were, and hence should not be bound in any way by those past beliefs.²⁸⁸

Our approach to balancing past and present preferences and values

5.29 As we set out in Chapter 2, we take a clear stance on some of these claims. We argue that a person with dementia is essentially the same 'person' as they were before they developed the condition,

²⁸⁴ See, for example, Dworkin R (1994) *Life's Dominion* (New York: Vintage Books), pp218–241; Dresser R (1995) Dworkin on dementia: elegant theory, questionable policy *Hastings Center Report* 25(6): 32–8.

²⁸⁵ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q13.

²⁸⁶ Opinion Leader (2008) *Deliberative Workshop on Dementia: A report prepared for the Nuffield Council on Bioethics* (London: Opinion Leader), p4.

²⁸⁷ See, for example, Dworkin R (1994) *Life's Dominion* (New York: Vintage Books), pp218–41; Michalowski S (2005) Advance refusals of life-sustaining treatment: the relativity of an absolute right *Modern Law Review* 68(6): 958–82; Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q13.

²⁸⁸ See, for example, Kitwood, T (1997) *Dementia Reconsidered: The person comes first* (Buckingham, UK: Open University Press); Jaworska A (1999) Respecting the margins of agency: Alzheimer's patients and the capacity to value *Philosophy & Public Affairs* 28(2): 105–38; Dresser R (1995) Dworkin on dementia: elegant theory, questionable policy *Hastings Center Report* 25(6): 32–8.

even if many aspects of their behaviour may have changed; that they should be valued in the same way as before (and hence should be entitled to expect that their wishes and preferences should also be taken seriously); and that they remain 'valuers': able to value particular experiences and relationships in a meaningful way even if they are no longer able to rationalise why this is the case.

5.30 However, as we also note in Chapter 2, the person with dementia has interests both in the promotion of their autonomy and in their general well-being. In difficult situations, like that of Mrs A, these interests come into direct conflict. Mrs A has expressed past preferences, in line with her long-standing view of herself, that she would not value life with dementia, and these views must be given serious consideration. Yet, once experiencing dementia, she clearly enjoys and values her life. We believe that *both* sets of preferences should be seen as expressions of Mrs A's autonomy, at different times in her life, and that neither can easily be preferred. In addition, Mrs A's well-being interests need to be taken into account, and her obvious enjoyment of life and lack of distress suggest that her well-being would best be promoted by providing medical treatment that has a good chance of extending her life without undue burdens. Again, however, Mrs A's well-being interests cannot simply take automatic precedence over her past expression of her autonomy interests.

5.31 So how should these conflicting interests be prioritised? Having established that neither autonomy nor well-being interests can automatically take precedence, and that autonomy interests can include current wishes even when the person lacks capacity for the specific decision, we argue that, in each case, it will be a matter of weighing up the relative *strengths* of these claims.²⁸⁹ Factors which should be taken into account would include:

- How important is the issue at stake? For example, maintaining a person's religious practice or moral beliefs (for example with regard to what they eat) is likely to have been much more important to them than issues of aesthetics, taste, or smartness of dress.
- How much distress or pleasure is it causing now? If maintaining a past belief is causing major distress, then it is likely that the person's current well-being and not their previous autonomy interests should take precedence.
- Consider the underlying values or beliefs on which the earlier preferences were based. Have they genuinely changed or can they be interpreted in a new light? It may be the case that the person is expressing 'old' views or preferences in a different way.
- Explore whether the apparent changes in preferences or values result from psychosocial factors (such as fear) or directly from the dementia (such as sexually disinhibited behaviour), or whether on the other hand they are linked with a genuine pleasure in doing things differently.

5.32 Early (and continuing) discussions on these issues shortly after diagnosis will clearly help both carers and professionals to obtain a greater understanding of the strengths of the beliefs and values held by the person with dementia at that time. This will enable an appropriate balance to be made between potentially conflicting interests if this later becomes necessary.

Recommendation 5: We recommend that the mental capacity Codes of Practice should be amended to provide additional guidance on how past and present wishes and preferences should be taken into account where these appear to conflict. This guidance should emphasise that neither past nor present can automatically take precedence, but that the relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider.

²⁸⁹ Hope T, Eccles J and Slowther A (2009) Best interests, dementia, and the Mental Capacity Act (2005) *Journal of Medical Ethics*, in press.

Advance decisions and advance care planning

5.33 We noted in paragraph 5.15 that the Mental Capacity Act makes provision for an ‘advance decision’ to refuse treatment, and that such a provision is planned for Northern Ireland. For example, a person might clearly state that if in the future they have dementia and are no longer able to recognise, or hold a conversation with, their close relatives, then they refuse any treatment which might extend their life (such as cardiopulmonary resuscitation) or be invasive in any way (for example, the insertion of a feeding tube). This decision would then be binding in the future, unless the person had clearly changed their mind while they still had capacity, or had done “anything else clearly inconsistent with the advance decision remaining [their] fixed decision” (see paragraph 5.39).

5.34 Advance decisions to refuse treatment, if they are ‘valid and applicable’, thus take priority over any consideration by family or professionals as to what might be in the person’s best interests, and make legal provision, in strictly defined circumstances, for a person’s past views to be binding. The scope for making advance refusals of treatment remains controversial, and the arguments surrounding them are based on very similar concerns to those highlighted above in our consideration of how past and present views and interests should be balanced in the determination of a person’s best interests (see paragraphs 5.27 and 5.28). On the one hand, it is argued that:

- an advance refusal gives a person control over important aspects of their life (including the right to act in a way which may not be in their own best interests out of altruistic motives) at a time when they would otherwise be completely disempowered;
- such a refusal can stop disputes within families and reduce distress and guilt among family members who would otherwise be forced to make very difficult decisions; and
- it would be a serious abuse of trust not to follow a person’s clear directions for their future care.²⁹⁰

5.35 On the other hand, it can be argued that:

- a person will not have sufficient information to make decisions for a future situation about which they know very little;
- no-one can predict how their own attitudes may change in the future, especially since important experiences such as serious disease may trigger a re-evaluation of what one values in life;
- advance decisions are unlikely in practice to be useful because of difficulty in applying the decision to the actual circumstances that arise, and because scientific and clinical developments may undermine the rationale for the person’s making the treatment decision; and
- it is inappropriate to attempt to bind one’s future self in such a specific way, regardless of the interests and preferences of that self.²⁹¹

5.36 These concerns may seem particularly acute in the case of dementia, compared with cases such as coma, where the person’s incapacity derives from their unconsciousness, because the person with dementia will retain the ability to feel emotion and experience the outside world, distress and pleasure. Moreover, the stigma of dementia and the fear of a frightening, joyless and undignified existence may lead people, either before diagnosis or shortly afterwards, to make assumptions about their future quality of life that may be significantly inaccurate.

²⁹⁰ See, for example, Dworkin R (1994) *Life’s Dominion* (New York: Vintage Books), pp218–41; Michalowski S (2005) Advance refusals of life-sustaining medical treatment: the relativity of an absolute right *Modern Law Review* 68(6): 958–82; Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q17.

²⁹¹ See, for example, Dresser R (1995) Dworkin on dementia: elegant theory, questionable policy *Hastings Center Report* 25(6): 32–8; Jaworska A (1999) Respecting the margins of agency: Alzheimer’s patients and the capacity to value *Philosophy & Public Affairs* 28(2): 105–38; Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q17.

- 5.37 The Mental Capacity Act 2005 attempted to address many of the concerns surrounding advance decisions by requiring that only a 'valid and applicable' advance decision would be legally binding. When professionals are faced with an advance decision refusing treatment that they believe to be in the best interests of the person with dementia, the question of whether the decision is 'valid and applicable' will be crucial. The criteria for validity include such issues as: did the person really make that decision; did they have capacity at the time; were they appropriately informed of the key information (that is, the information that would be required if a person with capacity were to refuse treatment at the time it was offered); and was the decision made voluntarily? Unless the advance decision is created in conditions that provide evidence on these issues, it will be impossible for professionals to know whether the decision is valid; we return to this issue in paragraph 5.41.
- 5.38 The issue of applicability will also be difficult to judge unless the decision is clearly specified. There may be details of the actual situation that arises that make it unclear whether the advance refusal applies. Consider an advance decision refusing all life-extending treatments when the person has advanced dementia. Suppose the person, in a state of advanced dementia, suffers an acute, life-threatening, allergic reaction to a bee sting. Does the advance decision constitute a valid and applicable refusal of treatment? Since the reaction is life-threatening, on one interpretation it is applicable, but whether this was the kind of situation that the person had in mind to include is not clear. In order to help professionals to carry out the genuine wishes of the person making an advance decision, it will be useful for the decision to include a statement about the values and reasons for the specific refusals of treatment. Such values and reasons will help in judging whether the refusal should apply to the actual situation that arises.
- 5.39 A further issue around validity arises where there is reason to believe the person may have changed their mind. The Mental Capacity Act provides that an advance decision will not be valid if the person making it has either withdrawn it while they had the capacity to do so or done anything "clearly inconsistent" with the advance decision remaining their fixed decision.²⁹² The Act does not spell out whether the person with dementia could invalidate their past decision by demonstrating changed attitudes *after* loss of capacity, for example by clearly demonstrating pleasure in life despite having made an advance decision based on a belief that they would find no value in a life with dementia. Academic legal writers have disagreed over this issue,²⁹³ and yet this is clearly a crucial point. If inconsistent behaviour *after* loss of capacity could invalidate an advance decision, this would reassure those who fear that an advance decision could lead to treatment decisions that do not respect the person's subsequent autonomy and well-being interests. However, it would be far from reassuring for those who make an advance decision precisely because they want to control their (incapacitated) future, regardless of how they may experience their lives at that future point in time.
- 5.40 We recognise that the ability to make binding advance refusals of particular forms of treatment generates very strong feelings on both sides of the debate. While we are concerned that, in some cases, people may complete advance decisions because of the stigma and fear associated with dementia (which we have sought to challenge in this Report), we also recognise that some individuals will still wish to avoid any prolongation of a life with dementia, however good the quality of care provided, or may have a strong wish not to be dependent on others. **If we are to promote people's interests in their own autonomy and well-being, and in particular in their own**

²⁹² s25(2) Mental Capacity Act 2005.

²⁹³ Michalowski S (2005) Advance refusals of life-sustaining medical treatment: the relativity of an absolute right *Modern Law Review* 68(6): 958–82; Maclean AR (2008) Advance directives and the rocky waters of anticipatory decision-making *Medical Law Review* 16: 1–22; Donnelly M (2009) Best interests, patient participation and the Mental Capacity Act 2005 *Medical Law Review* 17: 1–29.

notion of what constitutes their own well-being, then it is right that the law should, as at present, permit those who feel so strongly to make those wishes effective.

- 5.41 However, we remain concerned that in many cases an advance refusal of treatment may not operate in the way that the person in fact envisaged. We therefore welcome guidance on advance refusals such as that produced by the NHS End of Life Care Programme and the National Council for Palliative Care, which provides a model advance refusal form and suggests a number of helpful safeguards. These include: encouraging the person completing the form to discuss their wishes and fears with a health professional; encouraging the person to include information about their “hopes, fears and expectations of life”, which may help professionals later to determine whether the refusal is applicable in the circumstances or not; and confirming that the refusal does not apply to the offer and provision of basic care, support and comfort.²⁹⁴ We believe that such guidance may help those who wish to make advance refusals of treatment to formulate their wishes in a way which is more likely to be relevant and applicable at a later stage.
- 5.42 We are also concerned about the current lack of consensus as to whether an advance refusal made under the Mental Capacity Act could be invalidated by inconsistent behaviour after loss of capacity to make the decision in question. Such a lack of clarity adds to the concerns on the part both of those who wish to write binding refusals and of health professionals who have to act upon them.

Recommendation 6: We recommend that the Department of Health should act quickly to provide additional guidance in the Code of Practice on whether advance refusals may be invalidated by inconsistent behaviour *after* the person has lost legal capacity to make the decision in question.

- 5.43 While we accept that for some people their interests in being able to control their own future are so strong that it is right to permit advance refusals of treatment, we note that the ethical basis for this approach is closer to ‘negative’ ideas of autonomy (‘no interference’) than to the richer approach to autonomy which we promoted in Chapter 2. This richer approach emphasises the highly significant role which our relationships with, and dependence on, others play in the development and expression of our autonomy.
- 5.44 Drawing on our approach to autonomy, we would like to highlight the much broader concept of ‘advance care planning’ which is now seen as an important part of palliative and end of life care. The End of Life Strategy, published in July 2008 by the Department of Health in England, emphasises the importance of encouraging *all* people who may be approaching the end of their lives to discuss and document their wishes about their care,²⁹⁵ and the Scottish strategy *Living and Dying Well* similarly emphasises “creating opportunities to explore wishes and choices and help people plan for the future.”²⁹⁶ Such wishes can, of course, include the refusal of particular forms of treatment in particular circumstances. However, they may also include wishes about where the person would prefer to be as they are dying, the people they would most want to have around them and whom they would wish to be consulted about their care, and other aspects of their lives that they find most important and that may help make the end of their life as peaceful and supported as possible.

- 5.45 Guidance on end of life care for people with dementia published by the National Council for Palliative Care emphasises the need for such discussions to begin early, while the person with

²⁹⁴ NHS End of Life Care Programme and National Council for Palliative Care (2008) *Advance Decisions to Refuse Treatment: A guide for health and social care professionals* (Leicester: NHS End of Life Care Programme; London: National Council for Palliative Care).

²⁹⁵ Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for all adults at the end of life* (London: Department of Health), p12.

²⁹⁶ NHS Scotland (2008) *Living and Dying Well: A national action plan for palliative and end of life care in Scotland* (Edinburgh: The Scottish Government), paragraph 23.

dementia has the cognition and language to communicate their wishes more easily.²⁹⁷ Indeed, in the United States, the development of such ‘values histories’ is not specifically associated with end of life care: people at any stage of their life are encouraged to think about their values and make them known.²⁹⁸ This is enshrined in law through the Patient Self-Determination Act 1990, under which institutions such as hospitals, nursing homes and home care agencies are required to alert those using their services to their right under state law to make an advance directive about their future care wishes.²⁹⁹

- 5.46 While future care wishes other than advance refusals are not legally binding, any such clearly documented preferences should be taken seriously into account as part of any assessment of a person’s best interests in connection with either their clinical care or general welfare after capacity to make these decisions has been lost. Indeed, in England and Wales, the Mental Capacity Act requires that particular attention must be paid to a person’s written wishes when making a best interests judgment, thus suggesting that such wishes are likely to weigh heavily in the scales against any other considerations.³⁰⁰
- 5.47 We note that advance care planning enables a person to express their wishes about the kind of care and support they would prefer to receive at the end of their lives in a more holistic way than through a simple advance refusal of specific treatment. Indeed, a crucial difference is that, whilst advance decisions focus on limiting treatment options, advance care planning allows people to say what they do want and what their overall values are. A second important difference is that advance care planning is an ongoing process, not a decision made at a single time. We commend as an example the American *Five wishes* advance care planning document, which encourages those completing it not only to specify treatment they would or would not wish to receive, but also to highlight their preferences around physical and emotional comfort, their relationships with others, and their concerns for their loved ones.³⁰¹ We also note, and welcome, the national guidelines on advance care planning published in 2009 by the Royal College of Physicians and others, which include practical recommendations for the implementation of advance care plans, such as ensuring that they are kept in a special section of the person’s medical notes.³⁰²
- 5.48 **Where individuals wish to make decisions about their future care, we strongly support the notion that this is best achieved within the broader context of advance care planning.** We suggest that such planning should begin early, and should be regarded as an ongoing process and not as a one-off event, with any documented wishes regularly reviewed. We also highlight the possibility of nominating a ‘welfare attorney’, as discussed later in this Chapter (see paragraphs 5.53–5.63). Drawing on the concerns we have discussed in this Chapter around how an individual’s well-being and autonomy interests, past and present, can best be balanced, we suggest that the moral authority, validity and applicability of any advance decision or advance care plan would be enhanced if the following features were to be included:

²⁹⁷ The National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: The National Council for Palliative Care), p13.

²⁹⁸ See, for example, the Values History Form produced by the Institute for Ethics at the University of New Mexico Health Sciences Center, available at: http://hsc.unm.edu/ethics/docs/Values_History.doc; guidance issued by United States Department of Veterans’ Affairs: Pearlman R, Starks H, Cain K *et al.* (1997) *Your life, Your Choices: Planning for future medical decisions – how to prepare a personalized living will* (Washington: United States Department of Veterans’ Affairs), available at: http://www.ethics.va.gov/YLYC/YLYC_First_edition_20001001.pdf.

²⁹⁹ US House of Representatives, 101st Congress (1990) Patient Self Determination Act, s2(f); see, for example, www.ascensionhealth.org/ethics/public/issues/patient_self.asp.

³⁰⁰ s4(6)(a) of the Mental Capacity Act.

³⁰¹ See: www.agingwithdignity.org/catalog/nonprintpdf/Five_Wishes_Final.pdf.

³⁰² Royal College of Physicians (2009) *Advance Care Planning: National guidelines*, Concise guidance to good practice number 12 (London: Royal College of Physicians).

- the information available to the person writing the advance care plan about their medical condition and its prognosis;
- an acknowledgment of the uncertainty involved in the planning process: uncertainty about the medical prognosis, uncertainty about the availability of innovative new treatment, and uncertainty about how the person writing the plan may view things from a future perspective;
- an expression of care and concern for the well-being of the individual in the future, which may also emphasise the uniquely personal link between the individual now and in the future;
- an expression of care and concern for the welfare of those expected to be close to the individual in the future; and
- a statement of personal beliefs and values, including views about individual issues, personal accounts of life in narrative form, and any understanding of the nature and meaning of that life as a whole.

5.49 A more comprehensive and inclusive model of advance care planning on these lines would acknowledge the unique moral authority of the self while the person still has capacity, and also acknowledge the right of the person as they are 'now' to have the expression of their own, different perspective taken into account in judging what is in their best interests.³⁰³ When providing care we should make every effort to understand the desires, interests and values of people with dementia, especially as the disease reaches its most advanced stage. The voice of the person with severe dementia may be incoherent or muted, but we should do everything possible to interpret, encourage and enhance communication, whether verbal, non-verbal or behavioural, and we should treat all such communications with respect. We should value the views and opinions of people with dementia at all stages in their lives, and from the various, changing perspectives that they experience. Our approach to best interests should be an inclusive one, since the legal validity and moral authority of advance decisions are derived from the survival of the very person who made those decisions in the first place. We should seek to acknowledge and address the values and interests of that surviving person, as expressed in either the past or the present, however difficult a task that may be.

Pressure for assisted suicide and euthanasia

5.50 It is sometimes suggested that if people do not have confidence that they will be able to exert some control over their future health care at the end of life, they may prefer to consider suicide or some form of assisted dying as a way of taking more direct, personal control at an earlier stage in the illness. Some people find dementia particularly difficult to contemplate because of the characteristic effects of dementia on cognitive function, mood, behaviour and social awareness; and others may regard any future life with dementia as representing nothing but a burden to others.³⁰⁴ As a result, some (including a small minority of those responding to our consultation) argue for a change in the law to allow some form of assisted dying for those with dementia. Professional organisations in the UK such as the British Medical Association strongly oppose the legalisation of assisted dying, for various reasons, including arguing that the ongoing improvement in palliative care allows patients to die with dignity.³⁰⁵ The Royal College of Nursing, however, announced in July 2009 that on the specific issue of assisted suicide it was moving to a "neutral position... where the College neither supports nor opposes a change in the law to allow assisted suicide."³⁰⁶

³⁰³ Such an approach is also strongly in line with the spirit of the Mental Capacity Act Code of Practice, which stresses the importance of involving the person 'now' in decisions about their care – see, for example, paragraphs 5.21–4.

³⁰⁴ See, for example, Baroness Warnock's much publicised comments after an interview in a Church of Scotland magazine: Macadam J (2008) A duty to die? *Life and Work*, October, pp23–5.

³⁰⁵ British Medical Association (2009) *Assisted Dying: A summary of the BMA's position* (London: BMA), available at: www.bma.org.uk/ethics/end_life_issues/Assisdyingsum.jsp.

³⁰⁶ Royal College of Nursing press release (2009) *RCN moves to neutral position on assisted suicide* 24 July, available at: www.rcn.org.uk/newsevents/news/article/uk/royal_college_of_nursing_moves_to_neutral_position_on_assisted_suicide.

- 5.51 One of the components of our ethical framework is the belief that life with dementia can overall be positive. In Chapter 2 we have given our reasons for adopting this position. We recognise, however, that some people, when contemplating their own possible future with dementia, consider such a future, at least at some stage, as worse than death. The interest that people have in their earlier autonomous wishes being respected means that this must be taken seriously in decisions about health care if the person reaches a stage when they no longer have capacity to make health care decisions. Earlier in this Chapter, we discussed the situation where a person's prior wishes and current well-being might clash. Often, however, there will be no such dramatic clash: the person with severe dementia, near the end of life, may have autonomy interests, based on their past values, in not having life-prolonging treatment, and (unlike in the hypothetical case of Mrs A) their current well-being may be quite unclear. In such a situation it might be perfectly appropriate, and legal, for care to be aimed at keeping the person comfortable, but not to take active steps to prolong life where there is good reason to believe that treatment would be regarded as a burden by the person concerned, especially if there is doubt about the effectiveness of the treatment.
- 5.52 But should society legislate to permit active assisted dying for people with dementia, as a few of our respondents proposed? The present situation in the UK is that both assisted suicide and active euthanasia are illegal even where a person wishing to end their life has full capacity. We believe that in such circumstances it would be quite inappropriate even to start to consider any form of legal assisted dying in connection with dementia.

Proxy decision making

Creation of welfare attorneys

"[Ethical problems include] family conflicts over what is 'best' for the person with dementia; and the level of risk that different family members feel able to tolerate at the expense of the liberty of the person with dementia." *Alzheimer Scotland, consultation respondent*

"In general welfare attorneys are an excellent idea as they are appointed by the individual when they have full mental capacity." *Older People and Disability Team, Social Care and Learning Department, Bracknell Forest Council, consultation respondent*

- 5.53 We noted above (see paragraph 5.16) that it is now possible in both England and Wales and in Scotland for a person with capacity to nominate a 'welfare attorney' who will be empowered to take health or welfare decisions on their behalf if, in the future, they lose capacity to make those decisions themselves. As with advance decision making, this power enables a person with capacity to exert some control over their own future care, in that it permits them to choose a person, or people, whom they trust to make decisions on their behalf, and, indeed, to choose one person specifically rather than another. A welfare power of attorney is, however, a more flexible arrangement than an advance refusal of treatment, in that the welfare attorney will be able to weigh up all the relevant evidence at the time a decision is needed instead of having to 'second-guess' circumstances in the future.
- 5.54 It is clear, both from the responses to our consultation and elsewhere, that the possibility of nominating a welfare attorney has been widely welcomed. In its current review of the implementation of the Mental Capacity Act, the Office of the Public Guardian noted that the number of people applying to the Office to register a lasting power of attorney (the term used in the Act for the legal instrument nominating either a welfare attorney or a 'property and affairs' attorney) had significantly exceeded expectation,³⁰⁷ while the majority of LPAs made to date relate

³⁰⁷ Office of the Public Guardian (2008) *Reviewing the Mental Capacity Act 2005: Forms, supervision and fees – consultation paper CP26/08* (London: Ministry of Justice), p9.

to property and affairs, rather than welfare, this may be because people are still more attuned to the idea of future planning in the financial, rather than welfare, field.³⁰⁸ There have, however, been well-reported concerns about the complexity of the forms required to create an LPA; the cost of legal advice (which, while not strictly necessary, many people may prefer to take); the bureaucracy involved in 'registering' the power with the Office of the Public Guardian (without which it is ineffective) and the fees charged for this registration (£150 in 2008). In response, the Office of the Public Guardian has consulted on revised, simpler forms, and has proposed a reduced fee of £120. There are also arrangements for exemption or remission of fees for those on low income: people receiving welfare benefits such as Income Support are exempt from the fee, while those whose gross income is between £12,000 and £16,000 a year are entitled to reductions of between 25 and 75 per cent of the full fee.³⁰⁹

5.55 Welfare powers of attorney are a very good way of promoting a person's autonomy interests. Indeed, they have many advantages over an advance decision as they permit decisions to be made in the light of up-to-date knowledge both of the person's clinical needs and the care options available. We therefore welcome all attempts by the Offices of the Public Guardian to make welfare powers of attorney as accessible as possible to anyone who wishes to make one, in terms of ease of completion, level of bureaucracy and cost.

5.56 We believe that, in supporting and facilitating decision making on behalf of people who are inherently vulnerable as a result of their declining capacity, welfare powers of attorney represent a 'social good' and that, as such, they should, in principle, be available free of charge for everyone. At the very least, a funding mechanism should be found in order to ensure that when a person is first diagnosed with dementia, they are actively supported in nominating a welfare attorney if they so wish.

Recommendation 7: We recommend that the Offices of the Public Guardian in England/Wales and in Scotland actively monitor whether the current arrangements are in practice hindering anyone who might wish to benefit from appointing a welfare attorney from doing so, whether because of the cost or because of the complexity of the process. We further recommend that they work with the relevant Departments of Health to explore ways of actively supporting people to appoint a welfare attorney at the point when they receive a diagnosis of dementia.

Relationships between nominated proxies and professionals

"I don't feel that the view of a detached professional should override that of a spouse/partner/child/parent. How does a spouse etc, live with the feeling that they couldn't protect their loved one when it mattered most? Professionals will move on." *Jan Lethbridge, consultation respondent*

"Health care professionals must surely have precedence over attorneys in health care decisions ..." *Mrs Liz Purcell, consultation respondent*

5.57 Although welfare attorneys have the legal authority to make decisions on behalf of the person who lacks capacity, they do not have complete freedom of action: they are obliged by law to act in the individual's best interests (Mental Capacity Act) or be "satisfied that the intervention will benefit the adult" (Adults with Incapacity (Scotland) Act). This contrasts with the right enjoyed by

³⁰⁸ Between October 2008 and January 2009, the Office of the Public Guardian for England and Wales received 22,000 applications to register property and affairs LPAs and 6,000 applications to register health and welfare LPAs: House of Commons *Hansard*, 20 March 2009, column 1338W, available at: www.publications.parliament.uk/pa/cm200809/cmhansrd/cm090320/text/90320w0001.htm.

³⁰⁹ See: www.publicguardian.gov.uk/about/exemptions-remissions.htm for more detail. The income considered is that of the person making the power of attorney, not the person being appointed to act as the attorney.

individuals with capacity, to make decisions that appear eccentric or unwise to others, or which, for altruistic purposes, are in fact designed to benefit others rather than the individual concerned.

- 5.58 While in the vast majority of circumstances the requirement to act in the person's best interests will not be problematic, conflicts may arise in cases where the welfare attorney and health or social care professionals do not agree about the individual's best interests. This could occur in cases where there are different schools of thought about appropriate care, for example in the use of particular drugs to control behaviour that others find challenging. It could also arise because of the very different relationships and types of knowledge involved: while health care professionals are likely to consider best interests primarily from a clinical point of view, informed where possible by knowledge of the individual, welfare attorneys who are also close family members are more likely to consider the person's interests in the context of family relationships and family history. This may include not just the person's characteristics and preferences, but also a strong awareness of the concerns the person would have about the effect of decisions on others in the family circle. Indeed, we have emphasised throughout this Report that, in many of the difficult decisions that arise in dementia, there will be no single 'right' or 'best' answer. It is therefore hardly surprising that those involved in making a decision on behalf of the person with dementia do not always agree.
- 5.59 In England and Wales, the Mental Capacity Act Code of Practice offers some guidance on what health professionals should do if they disagree with a welfare attorney's decision, suggesting that they should discuss the case with other medical experts or get a formal second opinion before discussing the matter further with the attorney.³¹⁰ If agreement still cannot be reached, the Code of Practice suggests that the matter should then go to the Court of Protection. In Scotland, the Adults with Incapacity (Scotland) Act makes provision for a second opinion to be sought from a doctor nominated by the Mental Welfare Commission in the case of disagreement between the attorney and the responsible doctor, with the subsequent possibility of appeal to the Court of Session.³¹¹
- 5.60 The strict legal position under the Mental Capacity Act is that health professionals are only able to override the decision of a welfare attorney if they have court authority; or in order to provide immediately necessary treatment while awaiting the advice of a court; or if the person is detained under mental health legislation and is receiving treatment for their mental disorder.³¹² Overriding a welfare attorney's decision in other circumstances would potentially incur legal liability. Similarly, in Scotland, a doctor may only go ahead with treatment against the will of the proxy if authorised to do so by the nominated second-opinion doctor, if the treatment is required in an emergency, or if mental health legislation permits.³¹³
- 5.61 In practice, however, it is not clear whether welfare attorneys will feel confident in maintaining their own view as to the best interests of the person lacking capacity, or whether they will feel obliged to defer to professional views of best interests, even where they believe their own knowledge of the person will lead to a better decision. It is also not clear how well professionals understand their own role in cases where their assessment of a person's best interests and that of the person's welfare attorney differs significantly.³¹⁴
- 5.62 We noted in paragraph 5.53 that one reason why a person might choose to nominate a welfare attorney in case of their future incapacity is in order to exercise some form of control over their future. However, unlike decisions covered by advance refusals of treatment, the person is not

³¹⁰ Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (London: The Stationery Office), paragraph 7.29.

³¹¹ s50 Adults with Incapacity (Scotland) Act.

³¹² ss6 and 28 Mental Capacity Act.

³¹³ s50 Adults with Incapacity (Scotland) Act.

³¹⁴ See, for example, the discussion in Wrigley A (2007) Proxy consent: moral authority misconceived *Journal of Medical Ethics* 33: 527–31, where it is argued that in practice welfare attorneys are in fact no more than advisers.

necessarily trying to specify the *content* of any future decision, but is rather expressing trust in a particular named individual to make a decision on their behalf. While there is some research evidence to suggest that proxies do not always correctly predict what a person would, themselves, choose in a particular situation,³¹⁵ for many this may not be the key factor. Just as we suggested in Chapter 3 that the *way* services are provided may be more important than the actual service itself, in the case of proxy decision making the *person* making the decision may in many circumstances be more important to the person nominating the attorney than the decision itself. Thus, for example, more important than the actual content of decisions made for a man with dementia may be that fact that it is his wife who is making them. Equally, in some cases, the choice of a welfare attorney may be important in that *this* particular family member has been chosen in preference to another.

- 5.63 It would clearly be inappropriate to impose a blanket rule that a welfare attorney (or a welfare attorney who is also a close family member) should always have the final say. People with dementia who lack capacity are potentially highly vulnerable, and cases of possible neglect or abuse should never be overlooked. However, the values outlined in Chapter 2, in particular the importance of a person's autonomy interests (as expressed in this case through their choice of welfare attorney), strongly support the argument that the decisions of a welfare attorney should be decisive, unless health professionals have very serious concerns about the welfare of the person with dementia. Clearly this is not to say that health professionals who are concerned about a decision should not encourage discussion and, where appropriate, a second opinion. However, there should be much clearer advice to both attorneys and health professionals within the Code of Practice as to the authority vested in the welfare attorney.

Recommendation 8: We recommend that the Codes of Practice both for England/Wales and for Scotland should explicitly address the question of *when* it is appropriate for professionals to seek to override the decision of a nominated welfare attorney by approaching the Court of Protection, the Mental Welfare Commission or the Court of Session. Both professionals and welfare attorneys would then be clear as to their respective positions. Our view is that significant weight should be placed on the fact that the person on whose behalf the decision is being taken has actively chosen, in the past, to trust the welfare attorney to act on their behalf. This would suggest that others should seek to intervene only if they have grave concerns about the welfare of the incapacitated person, and not simply because they themselves take a different view of best interests.

How well are the Acts working?

- 5.64 In general, the evidence we received about the provisions of the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000 was very positive.³¹⁶ It was felt that the underlying approach to capacity – the presumption of capacity, the emphasis that capacity is decision-specific, and the awareness that capacity is not static – was empowering for individuals with dementia; that the Act had created a clear structure for decision making, which could be very helpful, especially where there was a lack of agreement within the family; and that the status of advance care planning had been enhanced, with the possibility of nominating a future decision maker through a welfare attorney being very popular.

³¹⁵ Ditto PH, Danks JH, Smucker WD *et al.* (2001) Advance directives as acts of communication *Archives of Internal Medicine* **161**: 421–30; Moorman SM, Hauser RM and Carr D (2009) Do older adults know their spouses' end-of-life treatment preferences? *Research on Aging* **31**(4): 463–91.

³¹⁶ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q18; The Working Party's fact-finding meeting with people on the front-line of dementia care, 10 July 2008.

- 5.65 While there were few challenges to the general principles of either Act, there were specific concerns about how they functioned in practice. Some felt that the bureaucracy involved was excessive, with the consequent risk that non-urgent but potentially beneficial treatment might not be given: it was suggested, for example, that flu vaccines were not given in some Scottish care homes because of the paperwork involved.³¹⁷ A number of respondents, particularly people working in health care, expressed concern about lack of knowledge and training, noting, for example, that some people working in the field still did not realise that capacity was decision-specific, and that without the right training and protocols staff may “make superficial and inadequate assessments of capacity.”³¹⁸
- 5.66 More generally, there is still some concern from Working Party members’ own experience that even though the mental capacity Acts have the ‘best interests’ or ‘benefit’ of the person at their heart, there is a risk that, in practice, a ‘tick-box’ culture may lead to the routine acceptance of unimaginative and unsympathetic decisions about that person’s care. **We argue in Chapter 2 that the difficult ethical problems which often arise in dementia do not lend themselves to formulaic answers, and that indeed there will often be no straightforward ‘right’ or ‘best’ answer. The approach to ‘best interests’ and ‘benefit’ set out in the mental capacity legislation and Codes of Practice is very helpful, in that it encourages a flexible approach to decision making that looks at the individuals and circumstances involved in each particular case. We reiterate here the fundamental importance of approaching such decisions not only with flexibility, but with compassion, founded on respect for the value of the person with dementia.**

³¹⁷ Christian Medical Fellowship, responding to the Working Party’s consultation.

³¹⁸ British Geriatrics Society, responding to the Working Party’s consultation.