Executive summary and recommendations

What is dementia? (Chapter 1)

1. The term ‘dementia’ describes a collection of signs and symptoms such as memory and communication problems, changes in mood and behaviour, and the gradual loss of control of physical functions which, taken together, are an indication of damage to the brain as a result of the progressive degeneration of nerve cells. This can be caused by a variety of different diseases, of which Alzheimer’s disease is the most common. Others include vascular dementia, Lewy body dementia, dementia related to Parkinson’s disease, frontotemporal dementia, alcohol-related dementias and prion diseases.

2. About 700,000 people in the UK currently have dementia, and this is likely to increase to 1.7 million by 2051. Its prevalence increases rapidly with age, affecting about one in five of us by the age of 85. In addition to its profound personal and social impact, dementia has significant financial implications for those with dementia, for their families and carers, and for our health care and social care systems. In the UK the overall annual economic cost of late-onset dementia is estimated at over £17 billion.

3. Dementia gives rise to many ethical questions affecting both the individuals directly involved – the person with dementia themselves together with their close family and friends who provide much of their support – and society as a whole. We now know much more about the damage to the brain that leads to the symptoms and behaviours of dementia, but we also have a growing awareness of the abilities and emotions which are retained long into dementia, despite serious cognitive losses. This increased understanding poses a strong challenge to past ideas of dementia as a ‘death that leaves the body behind’ and raises important questions as to the way in which people with dementia are currently regarded and respected. Yet this increase in knowledge has not yet delivered treatments which have more than a temporary effect. This lack of a ‘quick-fix’ solution challenges us to look more closely at how people can be supported to live well with dementia, how their experience of disability can be minimised, and the implications of this for both services and research.

4. Even with the best support, a person with dementia will experience profound effects in their life as a result of their disease. The decline in mental capacity and ability to function independently, together with the effect dementia may have on mood and behaviour, is highly distressing to the person with dementia themselves, and creates difficulties for carers as they seek to respond appropriately. The potential for frequent and serious conflicts of interest between the person being cared for and their carer or carers generates further ethical difficulties. The increasing number of people developing dementia means that many more people will be facing these questions in their own lives. This raises further ethical questions about how society supports people with dementia, and how it prioritises various forms of research into dementia.

An ethical framework (Chapter 2)

5. Those providing support and care for people with dementia face ethical problems on a daily basis: for example when balancing safety with freedom; deciding what is in the best interests of the person with dementia; and recognising that the needs of the person with dementia may sometimes conflict with the needs of others who also deserve consideration. While legal frameworks and guidelines are helpful in guiding practice and decision-making, they need interpreting and
applying to specific situations, and cannot provide precise answers to particular ethical problems. We propose an ethical framework, set out below, to help those who face these ethical problems, while emphasising that there is rarely a single ‘right’ answer in any specific situation. Our framework also provides a basis for the recommendations we make throughout this Report to those bodies whose remit affects the lives of people with dementia and their carers.

6. We emphasise, however, that guidelines and frameworks alone are not enough to provide proper support for carers, care workers and professionals. Education and support in ethical decision-making, in the form of ongoing professional education, courses and peer support, must be available to all those providing care on a paid basis, and to all carers who wish to access such support.

7. The framework that we propose in this Chapter has six main components, as set out in the box below.

Dementia: an ethical framework (Box 2.1)

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.

What is an ethical approach to care? (Chapter 3)

Some general points about the care of people with dementia

8. The concept of ‘supportive care’ is particularly helpful in dementia, in that it emphasises the need to support both the person with dementia and their family from the moment of diagnosis. In terms of our ethical values, such supportive care recognises the value of the person with dementia and is concerned to promote the well-being and autonomy of that person while also paying attention to the interests of carers. However, the ‘label’ attached to care is less important than the beliefs and attitudes underpinning that label. If care is provided on the basis that the person with dementia is valued as a person and supported to ‘live well’ with dementia, within the context of their own family and other relationships, then the label becomes immaterial.

9. We also emphasise two particular points which we believe to be especially important in dementia care. First, we argue that how things are done, so that people with dementia feel valued individuals, will often be far more important than the particular structure or format of services (paragraph 3.5). Secondly, we highlight the enormous importance of families and friends in the care of many people with dementia. It is our view that an attitude of working with
families and other carers, supporting them in their own care of the person with dementia, is most conducive to the interests of the person with dementia and best recognises the centrality of relationships with family and friends for many people with dementia. **We suggest that the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown within the family** (paragraph 3.12). Such a partnership would involve a relationship of trust between professionals and carers, based on mutual respect for each other’s role and expertise.

**An ethical approach to a care pathway for people with dementia**

Timing and communication of the diagnosis

10. The prevailing view at present is that diagnosis of dementia should be made as early as possible. Early diagnosis has a number of important benefits, but not every person with dementia will find that the advantages of early diagnosis and disclosure outweigh the disadvantages. We therefore emphasise the notion of ‘timely’ diagnosis, and suggest that diagnosis is likely to be timely at the point when the cognitive and other changes they are experiencing begin to affect their lives and the lives of people close to them. **We conclude that people should have access to good quality assessment and support from the time they, or their families, become concerned about symptoms that relate to a possible diagnosis of dementia** (paragraph 3.18).

We welcome the fact that improvements in early intervention and diagnosis are highlighted in the English dementia strategy and Scottish dementia priority paper but caution that the timeliness of a diagnosis will depend on the person and family concerned. We also emphasise that uncertainties about diagnosis should never be used as an excuse not to communicate openly with a person who is aware of changes in themselves and is actively seeking explanations. Respect for that person’s well-being and autonomy demands an honest response. There is, however, no value at present in attempting to screen for the underlying disease processes in the brain before symptoms of dementia appear.

11. There is some evidence to suggest that people in some cultural groups may be more hesitant in coming forward for diagnosis than those from others. Although individual choices and differences should be respected, it is important, given the potential benefits of earlier diagnosis, to understand the reasons that prevent people from coming forward. We suspect that feelings of shame and stigma associated with dementia play an important part in these reasons and that their significance varies between cultures.

**Recommendation 1:** We recommend that the UK Departments of Health should encourage more research to be carried out on the reasons why there is variation between cultures in readiness to come forward for diagnosis, and the role that misinformation and misunderstanding plays in these reasons. (Paragraph 3.19)

12. Whilst the principle of patient confidentiality is an important one in the doctor-patient relationship, a diagnosis of dementia has important implications not only for the person with dementia, but also for close family members who are likely to take on a significant caring role and need appropriate information and support to do so. **Professionals responsible for communicating a diagnosis of dementia should actively encourage the person with dementia to share this information with their family, making clear that the diagnosis is of importance to those providing informal care and support, as well as to the individual concerned** (paragraph 3.23). If the person with dementia refuses absolutely to allow information to be shared with others, this refusal must be honoured while the person has the capacity to make this decision. However, the professionals involved should make a careful assessment of the person’s capacity, and also make it clear to the person with dementia that it may be necessary to share information
with others later, once capacity to make this decision has been lost, in the interests of the person’s own well-being.

Recommendation 2: We recommend that the General Medical Council and relevant royal colleges, including the Royal College of Psychiatrists, the Royal College of Physicians, the Royal College of General Practitioners and the Royal College of Nursing, should consider ways of promoting an approach to the disclosure of a diagnosis of dementia that acknowledges the role of those close to the person with dementia, for example through the production of guidance on family involvement and confidentiality at the point of diagnosis. (Paragraph 3.24)

Information, communication and signposting to services

13. There is ample evidence that, in many cases, people are presented with a diagnosis of dementia and simply told to come back in a year’s time. It was argued forcefully in one of our fact-finding meetings with people in front-line dementia care that such a lack of information and support in the immediate aftermath of diagnosis is simply morally wrong. We agree (paragraph 3.26). Access to supportive care, including appropriate information, emotional support, and a variety of forms of practical support, is essential for people to live well with dementia, making the most of all their retained abilities.

14. People also need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services that people with dementia and their families may potentially use. We suggest that an important element will be the identification of a single individual to liaise with the person with dementia and their family, and with whom a trusting relationship can develop. We welcome the proposal in the English dementia strategy to pilot possible models of ‘dementia care advisers’, whose role would be to help people diagnosed with dementia access appropriate services and support. We suggest that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible (paragraph 3.27).

Ongoing care and support

15. We very much welcome the increasing emphasis on services which are flexible and appropriate to the individual, and which enable them to live well with dementia – an approach based on respect for the needs, preferences and personhood of the individual person with dementia (paragraph 3.31). A commitment to making services as flexible and responsive as possible does not necessarily entail spending more money; rather, it involves listening to the needs and wishes of the person for whom the service is being provided and adjusting the support on offer in order to help them in what they value most.

16. The ‘small things’ of care are particularly important in ensuring that care is genuinely supportive of the individual, and enhances that person’s autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.

End of life palliative care

17. End of life care for people with dementia is a matter of particular concern, with evidence to suggest that people with dementia are less likely to receive palliative medication, have
attention paid to their spiritual needs, or be referred to palliative care specialists than people who do not have dementia.

18. We note, and welcome, the fact that the English dementia strategy, the Scottish dementia priority paper, and the draft action plan for Wales all identify end of life care for people with dementia as an important target for improvement, and that the various UK end of life strategies similarly recognise the particular needs of people with dementia. It is clear that a key factor will be the development of models of end of life care which are appropriate to dementia, and we welcome the English dementia strategy’s commitment to the development and evaluation of such models (paragraph 3.45). We also strongly agree with the National Council for Palliative Care that close working locally between those responsible for dementia care and those responsible for end of life care is absolutely crucial.

**Dementia and society (Chapter 4)**

**Combating stigma and promoting inclusion**

19. Our emphasis on the equal value of people with dementia and the importance of acting in solidarity with those affected by dementia underpin a clear moral imperative to tackle the stigma which is still pervasive in dementia. Such stigma leads not only to difficulties and delays in accessing services but also to exclusion from mainstream society. While we strongly endorse the commitments in the English dementia strategy, Scottish dementia priority paper and Welsh draft action plan to improve public awareness, we believe that information and awareness campaigns are only one part of the story. For dementia to be truly normalised, it needs to become an accepted, visible part of our society, in the same way that physical disability is increasingly recognised as part of the norm.

20. People with dementia need to feel comfortable going to a club or out to lunch, participating in the life of a church, or taking part in voluntary work, just as they did earlier in their lives. “Service providers” such as shops, leisure services and restaurants have a legal duty under the Disability Discrimination Act 1995 to make “reasonable adjustments” to enable people with dementia to access those services. However, they will often not realise this, and even if they do, they are unlikely to have sufficient knowledge of dementia to make appropriate adjustments.

**Recommendation 3:** We recommend that the Equality and Human Rights Commission should give particular consideration to the discrimination currently experienced by people with dementia, and take appropriate action to publicise both the legal duties to which all “service-providers” are subject under the Disability Discrimination Act 1995 to ensure equal access to their services by people with dementia, and appropriate ways in which this could be achieved. In addition, the Disability Discrimination Act 1995 Code of Practice should explicitly address dementia with examples of good practice. (Paragraph 4.31)

**The role of society in providing care and support**

21. People with dementia experience a number of disadvantages in the current care system, especially in the way services are divided into ‘social’ and ‘health’ services. Many of their needs, for example for help with personal care, are classed as ‘social’, despite the fact that the direct cause of their symptoms is progressive damage to the brain. Under the current system, this means that support services may only be made available when a crisis has already been reached because of the pressure on social services departments to prioritise those in greatest need.
22. We argue in Chapter 2 that dementia is a medical disorder and that the needs arising out of the disorder should therefore be met in the same way as those arising out of other serious illnesses such as cancer. It is not acceptable to make people with cancer wait until their support needs have reached a crisis before providing that support and nor should it be regarded as acceptable for people with dementia to wait in this way. **The essential ethical point to be made is that the access of people with dementia to the services they need should not be determined by classifications of care.** In allocating resources, and in determining standards of care, it should make no difference whether the intervention is classified as ‘health’ or ‘social’ (paragraph 4.41).

**Making decisions (Chapter 5)**

23. 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 and general welfare, even if others disagree with the decision or believe that it is unwise. It is important to remember that people with dementia, especially in the earlier stages, will retain the capacity to make many decisions, especially when supported in doing so.

24. The Mental Capacity Act 2005 (covering England and Wales) and the Adults with Incapacity (Scotland) Act 2000 provide statutory frameworks for making decisions in cases where individuals do not have the capacity to make specific decisions for themselves. Similar legislation has been promised for Northern Ireland. In all three jurisdictions of the UK, a person is presumed to have legal capacity to make a particular decision, unless the opposite is demonstrated. Moreover a person may have the capacity to make one decision even if they lack capacity to make another. Where decisions are made for people who lack capacity, such decisions must be in the person’s ‘best interests’ (England and Wales) or have the potential to ‘benefit’ the person (Scotland).

**Difficulties around borderline and variable capacity**

25. In many cases, it will be very clear whether a person with dementia does or does not have the capacity to make a particular decision. However, there will be times when the person’s ability to make a particular decision will be difficult to determine. 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 over-ruled by others in the hope of protecting their best interests.

26. To avoid, or at least reduce, the problems inherent in borderline capacity, greater emphasis should be put on *joint* decision making with trusted family members. This might help bridge the gap between the time when a person with dementia is fully able to make their own decisions, and the time when formal proxy decision making becomes necessary on a regular basis. In our view, 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. 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 (paragraph 5.23).

**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. (Paragraph 5.23)
Determining best interests/benefit: balancing past and present

27. In order to determine the ‘best interests’ of a person who lacks capacity to make a particular decision (or how to ‘benefit’ that person in Scotland), those making the decision are required to consider both the past and present wishes and feelings of the person. However, sometimes past and present wishes may differ significantly.

28. Our ethical framework highlights the importance of promoting both the autonomy and well-being of a person with dementia. We suggest that both past and present wishes are an expression of a person’s autonomy, and that where these differ, neither can automatically be preferred. Well-being factors, such as the person’s general level of happiness are also important but again cannot automatically take precedence over the person’s interests in having their autonomy respected. We suggest that in such cases it will be a matter of weighing up the relative strengths of these claims. Factors which should be taken into account would include:

- How important is the issue at stake?
- How much distress or pleasure is it causing now?
- Have the underlying values or beliefs on which the earlier preferences were based genuinely changed or can they be interpreted in a new light?
- Do 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 are they linked with a genuine pleasure in doing things differently?

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. (Paragraph 5.32)

Advance decisions and advance care planning

29. The Mental Capacity Act also makes specific provision for people in England and Wales to make ‘advance decisions’ to refuse treatment, even if that treatment may be life-saving. Such decisions are legally binding on professionals if they are valid and applicable to the treatment in question. In Scotland, there is no specific reference to advance refusals in the legislation, but they are potentially binding under case law. The ability to make binding advance refusals of particular forms of treatment generates strong feelings: some see them as a welcome opportunity to exercise autonomy into the future, while others are concerned that they may lead to decisions about health care that could be harmful to the person in their future vulnerable state. Under the Mental Capacity Act, an advance refusal can be revoked (and hence is no longer valid) by a person at any point while they retain the capacity to make the decision in question. An advance refusal may also be invalidated by behaviour which is inconsistent with the refusal; however it is currently unclear whether this safeguard applies at any time, or only while the person retains legal capacity to make the relevant decision.

30. While we are concerned that, in some cases, people may complete advance decisions because of the stigma and fear associated with dementia (and 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 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 (paragraph 5.40).
31. 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 (paragraph 5.41). 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.

32. 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 (paragraph 5.42).

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. (Paragraph 5.42)

33. We also highlight the much broader concept of ‘advance care planning’ which is an important part of palliative and end of life care, and which aims to encourage all people who may be approaching the end of their lives to discuss and document their wishes about their future care. Wishes set out in an advance care plan may 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; 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.

34. 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 (paragraph 5.48). 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.

Pressure for assisted suicide and euthanasia

35. 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. While one of the components of our ethical framework is the belief that life with dementia can overall be positive, we recognise that some people, when contemplating their own possible future with dementia, consider such a future, at least at some stage, as worse than death. However 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: welfare attorneys

36. It is now possible in both England/Wales and 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. A welfare power of
attorney is 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. While the creation of the power of ‘welfare attorney’ has been widely welcomed, there have been well-reported concerns about the complexity of the forms, the bureaucracy involved in ‘registering’ the power with the Office of the Public Guardian, and the fees charged for this registration.

37. 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 (paragraph 5.55).

38. 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 (paragraph 5.56).

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. (Paragraph 5.56)

Relationships between nominated proxies and professionals

39. 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 (England and Wales) or in a way which will benefit the person (Scotland). This may lead to potential conflict between welfare attorneys and professionals if views differ as to what course of action will be best for the person. The strict legal position is that, in such cases, professionals may only override the attorney’s opinion in an emergency, with the authority of the Court of Protection (England and Wales) or, in Scotland, with the authority of a second opinion doctor nominated by the Mental Welfare Commission or of the Court of Session. However, there is little guidance for professionals as to what level of concern should trigger an approach to the Courts or the Mental Welfare Commission.

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. (Paragraph 5.63)
How well are the Acts working?

40. 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. However, even though the mental capacity Acts have the ‘best interests’ or ‘benefit’ of the person at their heart, we are concerned that, in practice, there is still a risk of a ‘tick-box’ culture, which may lead to the routine acceptance of unimaginative and unsympathetic decisions about a person’s care. We emphasise in our ethical framework that the difficult 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 (paragraph 5.66).

Dilemmas in care (Chapter 6)

Overview of our approach

41. As we emphasise in the introduction to our ethical framework, ethical dilemmas arise on a daily basis for all those providing care for people with dementia. Such dilemmas may arise in mundane situations, but they are problematic and stressful, and those providing care often feel isolated and unsupported in responding to them. Yet the way in which they are handled may have a significant effect on the quality of life of both the person with dementia and others surrounding them. Moreover, the problems arising in dementia are complex: there is rarely one over-arching value or consideration that can be used to solve them, and hence judgment has to be applied in the light of every particular case. In view of this, our general conclusions are as follows:

1. Specific guidelines, rules and laws have a particular but limited role to play: they may help to set a framework pointing to ways in which problems may be resolved but they can rarely provide a definitive answer to a specific dilemma. Any such guidelines will need to be interpreted in a flexible and compassionate way when applied to a specific situation, with a focus both on the interests of the individual with dementia and on the interests of others directly concerned.

2. Professionals are in a position to support both carers and care workers, in addition to facing ethical problems themselves. They should have access to ongoing education to help them in both these roles. Education in ethical decision making, however, should not be limited to those with ‘professional’ roles: care workers are required to respond to ethical problems as part of their daily work, and should have access to the ongoing education needed to equip them to respond appropriately.

3. All those involved in direct care – carers, care workers, health and social care professionals, and volunteers – should have access to forums for sharing and receiving support in making ethical decisions. Carers and volunteers who wish to access more formal courses in ethical decision making should be able to do so (paragraph 6.3).

Recommendation 9: We recommend that the UK Departments of Health consider, as part of their dementia strategies and workforce planning, how all those involved in direct care of people with dementia can access appropriate education and support in ethical decision making. (Paragraph 6.3)
The use of assistive technologies

42. Technologies such as ‘smart’ home adaptations, telecare, memory aids and monitoring or tracking devices may play an important role in enhancing the lives of people with dementia and their close family and friends. They may promote a person’s autonomy and well-being by enabling them to live more freely and more independently for longer. Concerns, however, have been raised about possible detrimental effects, such as intrusion on privacy, stigma (particularly with reference to tracking devices) and the risk of reduced human contact. All these issues have the potential to affect both a person’s autonomy, for example through feeling controlled or devalued, and their well-being, for example through impoverished human relationships.

43. Where the person with dementia has the capacity to choose for themselves whether to accept or refuse a particular technology, their decision should be respected. Where a person with dementia lacks the capacity to decide for themselves whether to make use of a particular technology, the relative strength of a number of factors should be considered on a case-by-case basis, including:

- the person’s own views and concerns, past and present, for example about privacy;
- the actual benefit which is likely to be achieved through using the device;
- the extent to which a carer’s interests may be affected, for example where they would otherwise have to search for the person with dementia in the streets at night; and
- the dangers of loss of human contact (paragraph 6.12).

Balancing freedom and risk

44. Taking risks is an inherent part of our everyday lives, and a life without any form of risk is unimaginable. Those caring for people with dementia however, may often feel the need to do all they can to reduce risk to an absolute minimum. Unfortunately, minimising risk often means forgoing benefits and restricting freedom, which in turn may be highly detrimental both to the person’s sense of autonomy and to their overall well-being.

45. It is clearly important that those providing care for people with dementia assess and manage risks appropriately. However ‘risk assessments’ can often focus only on the possible risks, without considering what opportunities and benefits are being forgone as a result. For this reason we believe that the term ‘risk assessment’ should be replaced by ‘risk-benefit assessment’.

Recommendation 10: We recommend that the UK Departments of Health and the four bodies regulating adult social care in the UK1 should require care providers to consider risks not in isolation but in the context of a risk-benefit assessment. Such risk-benefit assessments should explicitly take into account the well-being and autonomy of the person with dementia, as well as their need for protection from physical harm and the needs and interests of others. The term ‘risk assessment’ should be replaced by ‘risk-benefit assessment’ in order to highlight the importance of benefits which may be lost in the attempt to reduce risk. (Paragraph 6.17)

Restraint

46. ‘Restraint’ includes both using (or threatening) force to make a person do something that they are resisting, and restricting their movements, whether or not they resist. Restraint techniques include physically holding a person, using straps or lap belts to keep them in a chair, locking doors to prevent them going out unaccompanied, and using medicines to calm and control

---

1 The Care Quality Commission in England, the Care and Social Services Inspectorate Wales, the Care Commission in Scotland and the Regulation and Quality Improvement Authority in Northern Ireland.
a person’s behaviour. In some circumstances, the person with dementia may understand why a particular restraint is being suggested for their own safety and may consent to its use. In other cases, however, they may not be in a position to consent, or restraint may be used in order to control behaviour that others find difficult or alarming. In such cases restraint may be experienced as highly demeaning and distressing. Yet, at times, those caring for a person with dementia may see no alternative but to use restraint.

47. For people who lack capacity to consent, the Mental Capacity Act limits the use of restraint to circumstances where it is a “proportionate” response to the likelihood of the person suffering harm. There is, however, little guidance on what constitutes a “proportionate” justification for restraint, and carers in particular may sometimes find that a lack of outside help leaves them little choice but to restrain the person for whom they care in order to get on with essential household tasks such as shopping and cooking. Regulations governing restraint in care homes make clear that restraint should be used only on an exceptional basis, as a technique of last resort, and detailed practical guidance on how to achieve this aim has been published by the Mental Welfare Commission for Scotland. Nevertheless, there is considerable evidence that restraint is much more widely used in practice.

Recommendation 11: We recommend that the Office of the Public Guardian, in association with the Department of Health, provide additional guidance to carers on when restraint might be considered to be “proportionate”, either within the Mental Capacity Act Code of Practice or in the form of stand-alone guidance.

Recommendation 12: We recommend that the Commissions responsible for regulating social care within the United Kingdom ensure that detailed and practical guidance on the appropriate use of restraint in care homes, such as that produced by the Mental Welfare Commission for Scotland, is made readily available to all those working in this sector.

Recommendation 13: We further recommend that the UK Health Departments should draw specific attention to the importance of providing support to carers that will minimise the need for restraint in the domestic context, for example through guidance to health and social services organisations on needs assessment. (Paragraph 6.38)

Abuse by family and friends

48. The abuse of people with dementia by people caring for them raises particular ethical issues, because of the complex relationships and dependencies involved. While definitions of abuse differ, it is widely accepted that the concept extends beyond physical or sexual abuse to psychological and emotional harm, financial exploitation and neglect. A recent survey in the UK among carers of people with dementia found that one per cent of carers had hit or physically hurt the person for whom they cared within the previous three months. Thirty three per cent of carers, by contrast, reported behaviours such as significant levels of screaming or swearing at the person with dementia, which the authors categorised as psychological abuse.

49. The need to intervene in order to protect the person with dementia remains the same, regardless of the intent of the person causing the harm; however, the action necessary to protect the person may be quite different. While some abuse will undoubtedly be of a malicious and criminal nature, there is considerable evidence as to the role played by ignorance, stress, ill-health and exhaustion on the part of carers. Allegations or evidence of abuse must always be thoroughly investigated and action taken to protect the person with dementia. At the same time it must be recognised that abuse and neglect may be the result of unmanageable pressure on the carer. Our focus on solidarity emphasises the need both to act to protect the person with dementia and to support their carer where the person with dementia continues to
benefit from their care. We suggest that these concerns add further weight to the importance of providing appropriate information, advice and peer support services to all those caring for people with dementia, as highlighted in Chapters 3, 6 and 7 (paragraph 6.45).

The needs of carers (Chapter 7)

Introduction

50. A ‘carer’ is defined in the UK Government’s Carer’s Strategy as someone who “spends a significant proportion of their life providing unpaid support to family or ... friends.” Families and friends demonstrate practical solidarity in the care and support they provide to people with dementia, whether this is given primarily out of love, compassion, duty, a desire to reciprocate past support, or a combination of all of these. We suggest that solidarity similarly urges us (as individuals, families, communities and through the state) to support carers in their own exercise of solidarity with those for whom they care.

Joint support for the person with dementia and their carer

51. Our ethical framework emphasises the importance of giving close attention to the autonomy and well-being of carers, both for the benefit of the person with dementia and because carers matter in their own right. We also argue that autonomy should be seen in ‘relational’ terms: that is, that a person’s sense of self and self-expression should be seen as being firmly grounded in their social and family networks. In addition, most people would wish that their carer’s interests should be given considerable weight: their interests include their carer’s interests. When autonomy is understood in these terms, then in order to support a person’s autonomous wishes and values it will be necessary to support the whole family and social structure.

52. A diagnosis of possible dementia has implications that extend well beyond the individual receiving the diagnosis. Close family and friends, and especially the partner of the person with dementia, have to adjust to the ramifications for their own lives and come to terms with a shared future which may be very different from what they had all envisaged. An important implication both of our emphasis on solidarity and of our ‘relational’ approach to autonomy is to emphasise that professional support should have a wide focus that includes helping the family to support the person with dementia, rather than being limited to an exclusive and direct focus on the person with dementia (paragraph 7.19).

The need to be trusted

53. The issue of trust is central in any caring relationship. Most carers provide a level of care that compromises their own health and well-being, and are concerned to help and support the person with dementia as much as they are able. Given this trust-based relationship between the person with dementia and their carer(s), we suggest that unless there is evidence to the contrary, there should be a presumption of trust in carers by health and social care professionals and care workers. Such trust is a key part of any ‘caring partnership’, and without such trust it is highly unlikely that the person with dementia can be given the best possible support (paragraph 7.23).

Access to confidential information about the person with dementia

54. Concern has been expressed by many carers that professionals may be hesitant about sharing confidential information if the person with dementia lacks capacity to agree to disclosure, even where the carer feels that they need that information in order to make a proper decision on behalf of the person. The Mental Capacity Act Code of Practice sets out the legal position,
that information may be shared in such circumstances if it is in the best interests of the person who lacks capacity to do so, but suggests that carers who do not hold a power of attorney would not normally need such information as they have their own knowledge of the person to guide their decisions.

55. The Working Party strongly supports the current legal position that when a person lacks capacity, their confidential information should only be disclosed to others where it is in the best interests of the person to do so. We believe, however, that the current guidance in the Mental Capacity Act Code of Practice on when it will be in a person’s best interests to share information is too restrictive. Professionals should be made aware of the legitimate reasons why carers may ask for medical or other confidential information, and ordinarily start from the assumption that if a carer is involved in making a decision on behalf of the person with dementia, then they will need the same level of information as any other member of the care team. In short, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role (paragraph 7.26).

Recommendation 14: We recommend that the Office of the Public Guardian, in conjunction with the Department of Health and regulatory bodies such as the General Medical Council and Nursing and Midwifery Council, should reconsider the guidance on confidentiality currently given in the Mental Capacity Act Code of Practice, and give greater weight to the reasons why carers may need access to confidential information when involved in making decisions as to the best interests of the person with dementia for whom they care. (Paragraph 7.26)

Financial and social support

56. Caring for a person with dementia is expensive, encompassing factors such as lost earnings, paying for respite and other care, and investing in adaptations and assistive technologies for the individual for whom they are caring. Emotional and practical support is also crucial.

57. Our emphasis on solidarity highlights society’s responsibility to support people with dementia and their carers. This responsibility extends to informing carers, openly and systematically, of the social and financial support to which they are entitled: support should not only be available to those who know enough about the system and have sufficient persistence to assert their rights. We again commend the proposed role of a dementia care adviser or similar, who should be well placed to ensure that carers of people with dementia are better informed about their entitlements. We reiterate that a timely diagnosis is also important for carers, given that without such a diagnosis carers will experience significant difficulty in obtaining the help and support they themselves need (paragraph 7.30).

Considering one’s own interests

58. Carers need support in considering their own interests, as well as those for whom they care. When making a decision for a person who lacks capacity, others are legally required to act in that person’s best interests. At first sight, this suggests that the interests of the person with dementia should always be placed above those surrounding them. Yet interests are often complex and intertwined. In a family, it will rarely be the case that a single person’s interests always take priority: rather some consideration will be given to everyone’s interests and some degree of compromise found. Professionals such as doctors, nurses, clinical psychologists and social workers have an important role to play in supporting carers explicitly to consider their own needs and interests when weighing up difficult decisions, particularly around future care options (paragraph 7.37).
Research (Chapter 8)

How should research be prioritised?

59. The levels of funding available for dementia research have been strongly criticised, given both the prevalence and burden of dementia. The priority given to different forms of research within dementia (such as basic research, development of treatments, prevention, social science research and research into the quality of care) is also a key issue, especially as different types of research have the capacity to benefit quite different groups. Prevention and cure, for example, both seek primarily to benefit future generations, while research focused on quality of care has the potential to benefit people with dementia in the near future.

60. We are aware of the difficulties inherent in making comparisons between the funding available for research into dementia and funding available for other conditions. Nevertheless, we are struck by the fact that the major research funding bodies within the UK do not appear to have explicit policies according to which they allocate funds between different conditions, focusing rather on research excellence and the ‘importance’ of the topic. While it is clearly appropriate that funding bodies support important and high quality research, criteria such as these do not, alone, ensure a just distribution between the needs of different parts of the population. We believe that major research funders should be more explicit as to how they divide their research funds between areas of research that have the capacity to benefit very different groups of the population. Given the social and economic impact of dementia, we believe that a more explicit approach to research priorities would be likely to lead to significant increases in research funding for dementia. If such an increase were not to be matched by research applications of the necessary high standard, then active steps should be taken to develop and promote research capacity in the relevant areas (paragraph 8.17).

Recommendation 15: We recommend that the major research funders develop, and articulate, a reasoned basis for the division of their research funds between areas of research which have the capacity to benefit very different groups of the population. We further recommend that, if necessary, they take active steps to promote and sustain the creation of research communities capable of carrying out high-quality research. (Paragraph 8.17)

61. On the question of how funding should be prioritised within dementia research, we recognise that it is difficult to give one type of research priority over others. We would, however, make the following observations:

- Research into the effectiveness and transferability of different models of care and support for people with dementia is relatively neglected. Yet research into these areas is crucial if people are to be supported to live well with dementia. This is particularly important given that the prospect of a real cure for dementia is highly elusive.
- There are widespread concerns about the outcome measures used when assessing the effectiveness or cost-effectiveness of a particular treatment or service.
- It is crucial to understand better how people with dementia and their carers live with dementia, how dementia affects them throughout the course of the disease, and how their quality of life could be improved throughout those stages. Social research in this area is an essential starting point for both the research into care models and the development of sensitive outcome measures described above. More research into the effects of stigma and how stigma can best be challenged would also be highly valuable.
- All those involved in caring for people with dementia need better access to education and support in order to respond to the ethical problems they encounter on a daily basis. Further research is required on how best to achieve this aim.
- Research into non-Alzheimer’s dementias lags far behind that into Alzheimer’s disease.
Research into preventative strategies appears to receive too low a priority.

Recommendation 16: We recommend that relevant research funders consider ways in which the level of funding for dementia research could be increased in the following areas: health services research into how people with dementia and their carers can best be supported to live well, how mainstream services can best be adapted to their needs, and how good practice can more readily be implemented; more meaningful outcome measures for assessing the effect of particular forms of treatment or service; research into how best to improve the provision of support for ethical decision making; all forms of research for the non-Alzheimer's dementias; and research into preventative strategies.

Recommendation 17: We particularly highlight the importance of social research in providing an evidence base to underpin better ways of supporting people with dementia and their carers. We recommend that funding bodies such as the Economic and Social Research Council, in partnership with others, take active steps to encourage further research into issues such as how people live with dementia, the nature of their experience and the quality of their lives; how stigma can best be challenged; and how those working in health and social care can best be supported in providing care which genuinely respects the personhood of everyone with dementia. (Paragraph 8.18)

Who should be involved in research?

62. Individuals with the capacity to make their own decisions as to whether or not to be involved in research may be involved only if they give consent. The ability of people with dementia to make their own decisions (if necessary with plenty of support) as to whether or not they wish to participate in research should not be under-estimated. Particular difficulties arise, however, when involving people in research studies if they lack the capacity to make their own decision about participation.

63. There are clearly good ethical reasons, based on concern for people's autonomy and well-being, for ensuring that strong safeguards are in place to protect people who lack capacity from being harmed by research. However, at the same time there is a risk that, if the procedural bar is set too high, people with dementia will be excluded altogether from research. This, in turn, would be discriminatory: it would prevent people with dementia from acting altruistically when they have autonomously expressed a wish to do so, and would reduce the chance of better treatment and care both now and in the future. **We believe that the current legal safeguards are an appropriate way of protecting people with dementia from harm. However, we believe that action should be taken to make it easier to allow those who have expressed a wish to take part in research to do so** (paragraph 8.44). In particular, we highlight the following:

- The importance of good clinical trial networks which bring together clinicians and people with dementia who are interested in helping with clinical trials of promising interventions.
- The importance of researchers carefully considering the possible effects of the trial on the person with dementia beyond the end of the trial period.
- The potential benefits of people using advance decisions and advance care planning to state their views and wishes regarding their participation in research in the future. Such views and wishes could, with appropriate safeguards, provide a basis for participation in research at a time when the person lacks capacity to consent.
- The difference between the systems in England/Wales and Scotland as regards the power of welfare attorneys to consent to research: in Scotland welfare attorneys have this power while in England and Wales they do not.
Recommendation 18: We recommend that the UK Departments of Health should commission research on the feasibility of developing some form of (non-binding) advance statement on research participation which could influence decisions on research participation after loss of capacity.

Recommendation 19: We recommend that serious consideration be given to enable the role of the welfare attorney in England and Wales to be explicitly extended to include decisions over research, both within the Mental Capacity Act and the Clinical Trials Regulations. In the meantime we recommend that the Mental Capacity Act Code of Practice should provide guidance on the role of the welfare attorney in decisions about participation in research governed by the Mental Capacity Act.

Recommendation 20: We further recommend that the mental capacity Codes of Practice should include clear guidance on the procedures to be followed when capacity is lost during involvement in a research project covered by the Act, to minimise the risk of research results being compromised as a result of people dropping out of research despite their initial wish to participate. (Paragraph 8.44)

64. The general principles of research governance and consent are, we believe, broadly correct. The practice, however, can place unnecessary barriers in the way of research in dementia. In particular:

- The bureaucratic procedures around research ethics approval can be cumbersome for researchers. We encourage current attempts by the Department of Health to simplify the procedures, particularly in the context of low-risk research.

- The ability of people with dementia to give, or withhold, valid consent to research should not be underestimated. The information provided both in written and verbal form, however, may need to be provided in a different form for people with some cognitive impairment compared with people without such impairment. Both researchers and ethics committees should adapt the informing process in a way to enable, rather than to exclude, people with dementia in making a valid decision as to whether or not to participate in research (paragraph 8.45).