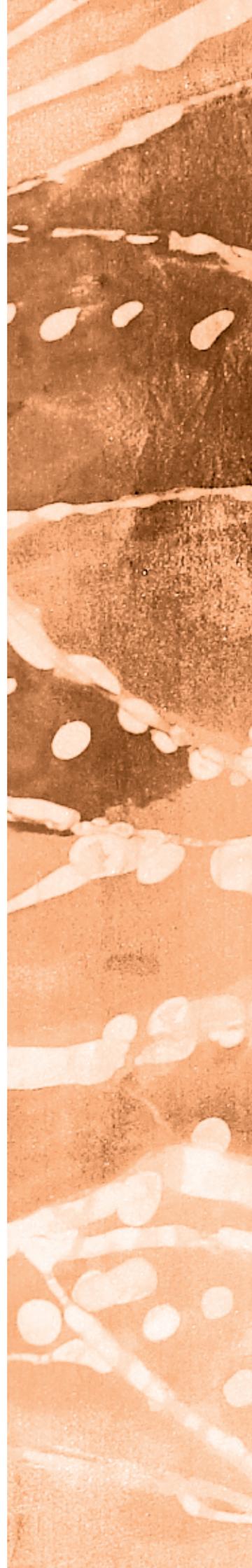


Chapter 3

What is an ethical approach to care?



Chapter 3 – What is an ethical approach to care?

Introduction

- 3.1 In the previous Chapter we put forward a framework to support ethical judgments in the context of dementia, while emphasising that there is rarely one right answer in any given situation. In this Chapter we will discuss how this framework might be practically applied in the day-to-day care of people with dementia, whether in their own homes, or living in some form of supported or residential care. We will then consider in turn various aspects of a 'care pathway' in the light of both our framework and the responses we received to our consultation. The care pathway experienced by any particular individual with dementia will, of course, vary considerably, depending on their own needs and circumstances and the availability of different kinds of support. By looking at scenarios which are likely to arise at various stages of dementia, including assessment and diagnosis, initial advice and support, ongoing support in the community, residential care and palliative care, we seek to suggest ways in which our ethical framework may help those providing care. We illustrate these by reference to services that have come to our notice where aspects of our ethical framework are being realised in practice. In doing this we are also aware that the research base for the relative effectiveness, cost-effectiveness, and transferability of different models of care and support services provided for people with dementia is still relatively limited,¹¹⁰ and hence it may not always be the case that services that are successful in one area can be readily imitated in another. We return to this issue in Chapter 8 (see paragraphs 8.8 and 8.18).
- 3.2 Guidance on standards and approaches to the care of people with dementia have recently been the focus of a number of major reports within the UK. In February 2006, SIGN produced a 'clinical guideline', based on a review of the best available evidence, setting out in detail how people with dementia and their carers should be supported by health and social care professionals in Scotland.¹¹¹ Later in the same year, NICE and SCIE published a similar guideline for England and Wales.¹¹² In 2008, the Scottish Government declared dementia a national priority, setting a target of 2011 for all health boards to deliver improvements in early diagnosis and management of people with dementia,¹¹³ and subsequently promising a dementia strategy.¹¹⁴ In February 2009, the Department of Health in England published a 'National Dementia Strategy', seeking to address three main themes: raising awareness; early diagnosis and intervention; and improving the quality of care.¹¹⁵ In Wales, a draft National Dementia Action Plan is subject to consultation until September 2009,¹¹⁶ while in Northern Ireland, the NI Executive has noted the "200 per cent increase in dementia" expected over the next ten years, and promised to work with housing and health authorities to address the needs of people with dementia.¹¹⁷ We briefly summarise the conclusions of NICE/SCIE guidance, the Scottish

¹¹⁰ See, for example, Burns A and Robert P (2009) The National Dementia strategy in England *British Medical Journal* **338**: 614 and the research recommendations in SIGN (2006) *Management of Patients with Dementia: A national clinical guideline* (Edinburgh: SIGN), paragraph 6.4.

¹¹¹ SIGN (2006) *Management of Patients with Dementia: A national clinical guideline* (Edinburgh: SIGN).

¹¹² NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE).

¹¹³ NHS Scotland (2008) *Mental Health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government).

¹¹⁴ Scottish Government news release (2009) Care for dementia, 28 May, available at: www.scotland.gov.uk/News/Releases/2009/05/27152029.

¹¹⁵ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health).

¹¹⁶ Welsh Assembly Government (2009) *National Dementia Action Plan for Wales*, consultation draft (Cardiff: Department for Health and Social Services).

¹¹⁷ Northern Ireland Government news release (2008) *Two hundred per cent increase in dementia in next ten years needs addressed says Ritchie*, 31 Jan, available at: www.northernireland.gov.uk/news/news-dsd/news-dsd-january-2008/news-dsd-310108-two-hundred-per-cent.htm.

National Priority Summary Paper, the English National Dementia Strategy and the draft National Dementia Action Plan for Wales (see Boxes 3.1–3.4 below) and, while we broadly endorse their main conclusions and recommendations, we go on to make further observations and recommendations in the light of the ethical framework we have set out.

Box 3.1: NICE/SCIE guidance on health and social care support for people with dementia – key priorities

Non-discrimination: people with dementia should not be excluded from any service because of their diagnosis, age, or co-existing learning disabilities.

Valid consent must be sought from people with dementia. If the person lacks capacity to make a particular decision, then the provisions of the Mental Capacity Act 2005 should be followed.

Carers should receive an assessment of their own needs, and carers experiencing psychological distress should be offered psychological therapy from a specialist.

Health and social care services should be integrated and care plans endorsed by the person with dementia and/or their carers.

Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.

Structural imaging (MRI or CT scanning) should be used in the assessment of people with suspected dementia, to exclude other causes of their symptoms and to help establish their specific diagnosis.

People with behaviour that challenges should be offered an early assessment to identify the likely factors that may generate, aggravate or improve the behaviour. Individual care plans should then be developed and regularly reviewed.

Dementia-specific training should be available to all staff working with older people in the health, social care and voluntary sectors.

Acute and general hospitals should plan and provide services that meet the specific needs of people with dementia who need to use hospital services for whatever reason.

NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE).

Box 3.2: Objectives in the Scottish National Priority Summary Paper

- Improvements in early diagnosis and management of people with dementia;
- Improving standards of care through 'integrated care pathways' for dementia;
- Production of information about coping with dementia for people with dementia and for carers;
- Development of appropriate post-diagnostic support services;
- Improving quality of life in hospital and other care settings;
- Improving palliative care;
- Encouragement of 'dementia-friendly' premises;
- Supporting staff, with guidance published on the knowledge, skills and values needed by nurses working with older people's mental health services;
- Raising public awareness; and
- Development of a Scottish Dementia Research Network.

NHS Scotland (2008) *Mental Health in Scotland: Dementia: A national priority summary paper* (Edinburgh: The Scottish Government).

Box 3.3: Objectives in the English National Dementia Strategy

1. Improving public and professional awareness and understanding of dementia;
2. Good-quality early diagnosis and intervention for all;
3. Good-quality information for those with diagnosed dementia and their carers;
4. Enabling easy access to care, support and advice following diagnosis;
5. Development of structured peer support and learning networks;
6. Improved community personal support services;
7. Implementing the Carers' Strategy;
8. Improved quality of care for people with dementia in general hospitals;
9. Improved intermediate care for people with dementia;
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers;
11. Living well with dementia in care homes;
12. Improved end of life care for people with dementia;
13. An informed and effective workforce for people with dementia;
14. A joint commissioning strategy for dementia;
15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers;
16. A clear picture of research evidence and needs; and
17. Effective national and regional support for implementation of the Strategy.

Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health), pp12–3.

Box 3.4: Objectives in the draft National Dementia Action Plan for Wales**Strengthening individuals:**

- Provide good quality information for people with dementia and their carers;
- Acknowledge and support carers as key partners in the care of people with dementia;
- Increase housing options;
- Maximise use of telecare and assistive technology;
- Improve dementia care in the home;
- Provide appropriate end of life care.

Strengthening communities:

- Increase awareness and understanding;
- Improve the skills of the dementia workforce;
- Improve community crisis intervention;
- Ensure effective joint planning and commissioning.

Improving infrastructure and access to services for all:

- Ensure timely diagnosis;
- Ensure appropriate use of anti-psychotic medication;
- Ensure appropriate medicines management;
- Improve dementia care in general and community hospitals;
- Improve dementia care in mental health hospitals;
- Improve continuing health care;
- Improve access to intermediate care.

Making structural changes to economic, cultural and environmental conditions:

- Promote healthy living initiatives in dementia;
- Promote dementia research;
- Take action to ensure the National Plan is implemented.

Welsh Assembly Government (2009) *National Dementia Action Plan for Wales*, consultation draft (Cardiff: Department for Health and Social Services), pp9–11.

Some general points about the care of people with dementia

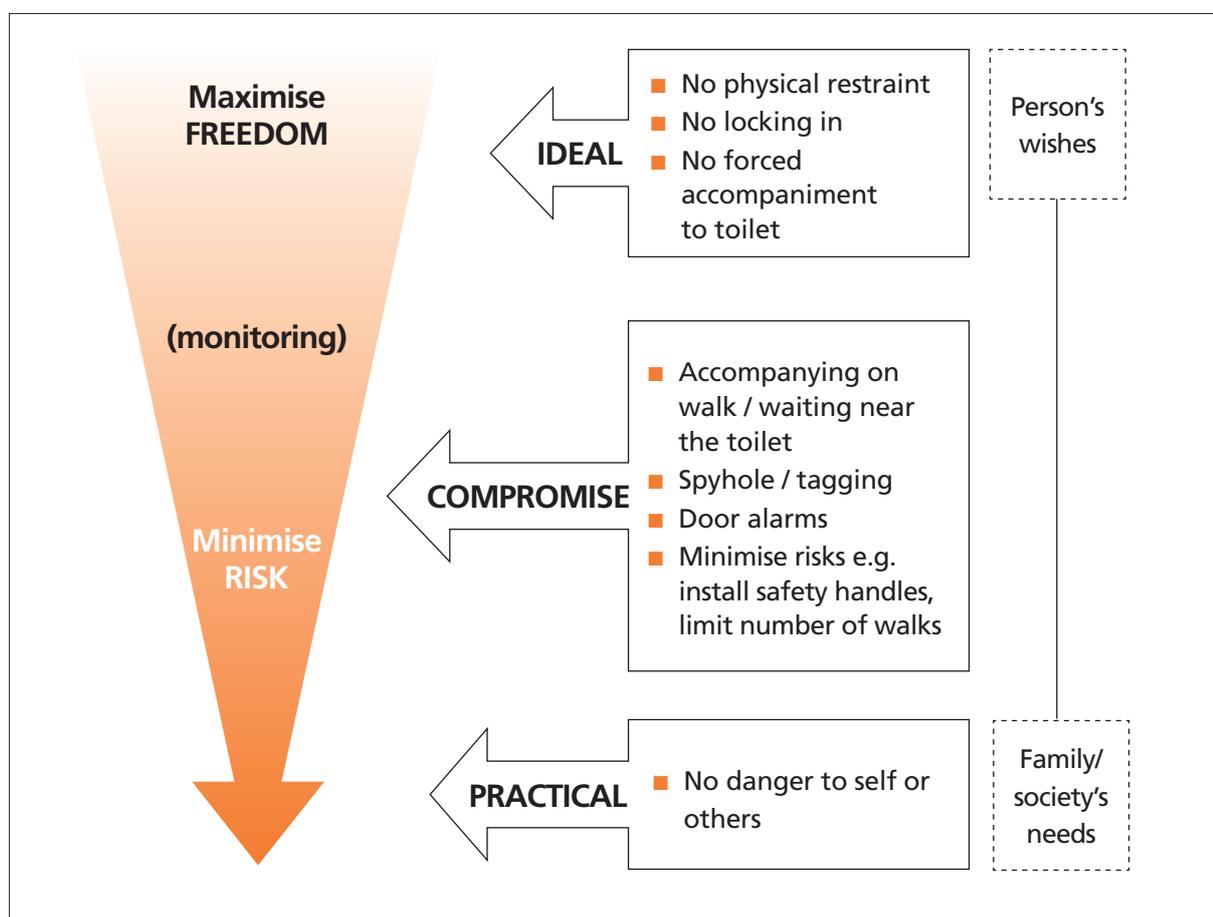
“If you really want to help somebody, first of all you must find him where he is and start there. This is the secret of caring.”¹¹⁸

- 3.3 We argued in Chapter 2 that while dementia is a disorder that is harmful, nevertheless a good quality of life is possible with dementia if the person with dementia is seen and respected as a person with values and interests towards whom we have the same duties as any other fellow human beings. We have also suggested that amongst the key values underpinning our approach to dementia should be concern for the autonomy and well-being of the person with dementia, coupled with an attitude of solidarity based on the belief that we are all ‘fellow-travellers’ and dependent, to various degrees at different times in our lives, on each other. How can these values be translated into practice on a day-to-day basis in a care environment?
- 3.4 It will not always be possible to provide services, or support individuals, in a way which fully respects all these values. Some degree of compromise between maximising autonomy and well-being may sometimes be necessary, for example when a person would be at significant risk of harm if they were not restrained in some way. Balancing the interests of the person with dementia with the interests of carers is also sometimes necessary. In many cases the role of support will be central in how the balances and compromises are managed. For example, as the diagram below shows,¹¹⁹ the participants in our public deliberative event tackled ethical problems by starting with an ‘ideal’ position of what the person most wanted and valued; then they considered what risks this posed (both to the person with dementia and others); and finally they put forward suggestions of support

¹¹⁸ Kierkegaard S (1998) The point of view, in *Kierkegaard's Writings Volume XXII* (Princeton: Princeton University Press), part 2, chapter 1A, paragraph 2.

¹¹⁹ Adapted from Opinion Leader (2008) *Deliberative Workshop on Dementia: A report prepared for the Nuffield Council on Bioethics* (London: Opinion Leader), p16.

or adaptations which could maximise the ideal position with minimum risk. In doing so, they demonstrated clearly that it was possible to come to a conclusion that recognised the importance of the various values, without prioritising one at the expense of another.



3.5 Moreover, the responses we received from our various consultative activities¹²⁰ suggest that the 'small' things – the 'micro' aspects of life and their effects – are of considerable significance both to autonomy and well-being. Quality of care and ethical issues are at least as much to do with the everyday as they are with the 'big' questions around the end of life. **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.** These 'micro' aspects of care are often primarily a question of *attitude*, of professionals and care workers genuinely believing that the person with dementia for whom they are providing care matters as an individual, and is a 'person' in the fullest sense of the word. Such attitudes emerge in such mundane, everyday circumstances as whether a care worker in a residential setting checks whether the person with dementia would like sugar in their tea, or encourages them to express preferences in the clothes they put on in the morning.

3.6 The term *person-centred care* is widely used as a guiding principle in dementia care, following the pioneering work in dementia by Tom Kitwood, who argued both for the recognition of the 'person' in every individual, however advanced their dementia, and for the central place in dementia care of creating and sustaining meaningful relationships.¹²¹ There were mixed, and to some extent polarised, views about the principle's value from respondents to our consultation, with some

¹²⁰ For example, in the Working Party's fact-finding visit to Vale House on 30 Sept 2008; see also Abbot W and Dugdale C (2005) It's the little things... *Journal of Dementia Care* 13(6): 12–4; Commission for Social Care Improvement (2008) *See Me, Not Just the Dementia: Understanding people's experiences of living in a care home* (London: CSCI).

¹²¹ Kitwood T (1997) *Dementia Reconsidered: The person comes first* (Buckingham, UK: Open University Press).

concerns that over time the term had lost its original meaning and had become more associated with ideas of consumer choice. One respondent called it an idea that was initially “inspirational” but “now abused and ... exhausted by overuse.”¹²² Many found it bland or obvious. In so far as the term emphasises the importance of promoting each person’s autonomy and well-being, it seems to us a useful concept. Any care which is genuinely tailored to the individual is likely to be culturally competent, in that it should take account of factors such as a person’s language, religious beliefs and observance, cultural practices, social care support and coping mechanisms.¹²³ Care which is genuinely ‘person-centred’ may also help to emphasise the importance of what we have called the ‘micro’ aspects of life. We are aware, however, of the concern that the term may have become debased and used to describe almost any care, regardless of the extent to which it is based on a genuine relationship with, and concern for, the individual, and that therefore the term may have lost much of its original value as a guiding principle.

- 3.7 More recently, it has been argued that a *palliative care* approach would best support people with dementia. While for many, ‘palliative’ care is perceived as care at the very end of life, international definitions emphasise its applicability from the moment when a person is diagnosed with a life-threatening illness. The World Health Organization, for example, defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹²⁴ The emphasis placed in palliative care on treating the ‘whole’ person, not only their physical pain or difficulties, but also their mental, social and spiritual needs, is clearly relevant in the care of people with dementia, as is the emphasis that care should extend beyond the person with the illness to their family.
- 3.8 While the palliative care approach is widely admired, it is sometimes seen as relevant only when all attempts to ‘cure’ the person, or maintain their current state of health, have failed. In the context of cancer treatment, for example, a person may be referred for palliative care only when other forms of treatment are no longer possible or desirable. As a result, the idea of *supportive care* throughout an illness has been developed in order to avoid the stark distinction between ‘active treatment’ while a cure still seems possible and ‘palliative care’ when all hope of cure has been given up.¹²⁵ Instead, it is argued that supportive care, focusing on making the quality of the person’s life as good as possible, should be provided throughout a person’s illness, in addition to any available treatment for the disease itself. This concept of supportive care is clearly applicable to *any* serious condition which affects a person’s quality of life; indeed, we were struck by how one person with dementia who gave evidence to the Working Party commented about the complete lack of supportive care she had received after her diagnosis, contrasting her situation with someone with a diagnosis of cancer.¹²⁶
- 3.9 Those promoting supportive care suggest that, once a person has received a diagnosis of a life-threatening illness, the care and treatment provided should be thought of as consisting of three components:

¹²² Professor June Andrews, Director, The Dementia Services Development Centre (DSDC), University of Stirling, responding to the Working Party’s consultation.

¹²³ Iliffe S and Manthorpe J (2004) The debate on ethnicity and dementia: from category fallacy to person centred care? *Aging & Mental Health* **8**(4): 283–92.

¹²⁴ For the World Health Organization’s definition of palliative care, see: www.who.int/cancer/palliative/definition/en/.

¹²⁵ Ahmedzai SH (2005) The nature of palliation and its contribution to supportive care, in *Supportive Care in Respiratory Disease*, Ahmedzai SH and Muers MF (Editors) (Oxford: Oxford University Press), pp3–38; Ahmedzai SH and Walsh D (2000) Palliative medicine and modern cancer care *Seminars in Oncology* **27**(1): 1–6; Hughes JC, Lloyd-Williams M and Sachs GA (Editors) (2010) *Supportive Care for the Person with Dementia* (Oxford: Oxford University Press, forthcoming).

¹²⁶ The Working Party’s fact-finding meeting with people at the front-line of dementia care, 10 July 2008.

- 1 *Disease-directed therapy*, which tackles the disorder itself;
2. *Patient-directed care*, which covers the more general support the person might want or need, including pain relief, rehabilitation, practical and psychological support, and information;
3. *Family-directed support*, which includes supporting the family in its caring role and also bereavement support after the patient's death.

'Supportive care' emphasises the importance of responding to the particular needs of the individual and those close to them, both in cases where treatment is available to tackle the underlying disorder and in cases where no such treatment as yet exists. It also emphasises the need to start support from the moment of diagnosis, again regardless of the availability of drug or other treatment to tackle the underlying disorder.

- 3.10 These three approaches – person-centred care, palliative care and supportive care – are all based on strong underpinning beliefs about the value of the person with dementia and the importance of all aspects of their being: their mental and physical well-being, their sense of self, their cultural and social background, their relationships, and their spiritual needs. The concept of supportive care appears to be 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, regardless of the availability or appropriateness of treatment for the underlying brain disorder. In terms of our ethical framework, 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, we note that 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.
- 3.11 A further issue stems from the importance of families and friends in the care of many people with dementia, as highlighted in the description of supportive care above. Most people with dementia are living in their own homes, with support from close relatives and friends. As we highlight in our discussion of solidarity (see paragraphs 2.43–2.47), an important aspect of the role of professionals is to provide support for *all* those affected, both in the sense of enabling the person with dementia to function and contribute as part of their family or social unit, and in the sense of providing support for family members and friends both in their caring role and in their own right. Indeed, in some older couples where one person has dementia and the other has other long-standing illnesses, there will be a strong element of interdependence: both may be 'carers' and 'cared-for' at the same time and need support for both aspects of their role.
- 3.12 During the consultation process we heard accounts from relatives where professionals appeared to treat them with suspicion or where information that would be useful in their caring role was not provided because of concerns about confidentiality.¹²⁷ We believe that an attitude of working *with* families and other carers, supporting them in their own care of the person with dementia, is more conducive to the interests of the person with dementia and better 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.** Such a partnership would involve a relationship of trust between professionals and carers, based on mutual respect for each other's role and expertise. We return to this issue in more detail in Chapter 7 (see paragraphs 7.20–7.23).

¹²⁷ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q28.

3.13 High-quality support and care for people with dementia and their families can only become a reality if the interests of professionals and care workers are also properly considered. As we highlighted in Chapter 2 (see paragraph 2.42), those who provide formal care services need to be properly equipped to do their job through appropriate initial and ongoing education. There is, however, considerable evidence as to the lack of such dementia-specific education both in undergraduate professional training and for care workers who are expected to provide hands-on care for people with dementia.¹²⁸ The commitment to workforce development in both the English dementia strategy and Scottish dementia priority paper is therefore particularly welcome.¹²⁹ Moreover, working in dementia services will often be emotionally challenging, and a key part of the support people working in this field may need is access to some form of peer support network or 'caring community' where support and advice from those in similar situations may be sought.¹³⁰

An ethical approach to a care pathway for people with dementia

Timing and communication of the diagnosis

"Early diagnosis is so important – so that I am involved in planning my future." Nancy McAdam, consultation respondent

"I was told very early that I have dementia. It was too early. My life would have been much easier without knowing my diagnosis." Ernie Allan, consultation respondent

"Admiral Nurses felt it was not so much about when the diagnosis was imparted (although we are clear it does need imparting as soon and as early as possible), it was more how it is imparted and how the person with dementia and their family are supported emotionally pre and post diagnosis." Admiral Nurses – 'for dementia', consultation respondent

Paul is 75. He is married to Marie, who is 73. For the last few months he has noticed that his memory is not what it used to be. He has had problems remembering names of people he knew well, and more recently with naming simple objects in the house. He has even forgotten a couple of bowls matches in which he was due to take part, and is becoming quite worried about his memory problems. He has mentioned these worries to Marie, but puts his problems down to the fact that he is just getting old. However, when his son came to stay last weekend with the grandchildren, his son said he should go and get a check-up with his GP. Paul is not too sure what to do. He tends to be quite pragmatic and get on with things and doesn't want to bother the doctor. However, if he is honest, he is also a bit scared. What if there is a problem and they cannot do anything about it? Wouldn't it be better to remain in ignorance? Or should he see someone in case something can be done to help him?

3.14 The prevailing view at present is that a diagnosis of dementia should be made as early as possible, and that it should be communicated directly to the individual, unless there are good reasons in a particular case to believe that the person would not want to know.¹³¹ This approach was strongly supported by the majority, though not all, of the respondents to our consultation. We were told of many instances of the concerns of relatives or the person themselves that 'something was wrong' being incorrectly dismissed by general practitioners or hospital doctors. This left people

¹²⁸ See, for example, Dementia Services Development Centre, University of Stirling (2006) *The Need to Know: A survey of course input at pre-registration/undergraduate level on dementia* (Stirling: DSDC); All-Party Parliamentary Group on Dementia (2009) *Prepared to Care: Challenging the dementia skills gap* (London: Alzheimer's Society).

¹²⁹ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health); NHS Scotland (2008) *Mental Health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government).

¹³⁰ See, for example, Aase M, Nordrehaug and Malterud K (2008) "If you cannot tolerate that risk, you should never become a physician": a qualitative study about existential experiences among physicians *Journal of Medical Ethics* 34: 767–71.

¹³¹ See, for example, the English dementia strategy, summarised above and in Box 3.3; National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), pp7–9; SIGN (2006) *Management of Patients with Dementia: A national clinical guideline* (Edinburgh: SIGN), paragraph 5.1.1.

with early dementia, and their families, without access to support. There are a number of benefits of early diagnosis, highlighted both by our respondents and in the research literature: the relief of understanding what is happening (both for the person with dementia and those close to him or her); the opportunity of accessing appropriate support services, including welfare benefits; the advantages of having time to plan; and the value of developing a trusting relationship with professionals.¹³²

- 3.15 One problem at the very early stages of dementia is the uncertainty of diagnosis. It is currently very difficult to predict whether a person with 'mild cognitive impairment' will progress fairly rapidly to dementia, or whether they will never do so. Although there have been some developments in the use of biomarkers in this area,¹³³ it is not yet clear how results from small-scale studies in research centres will work in larger populations. Moreover, a reliable diagnosis may take some time, owing to the need to evaluate the implications and progress of the symptoms, and it may also be necessary to re-evaluate a provisional diagnosis in the light of new information. A wrong or premature diagnosis of dementia may lead simply to unnecessary distress and worry and indeed more practical difficulties, such as the potential loss of a person's driving licence or difficulties obtaining insurance.
- 3.16 Even where there is little doubt about the accuracy of the diagnosis, it cannot be assumed that every person with dementia will find that the advantages of early diagnosis and disclosure outweigh the disadvantages. A distinction between 'early' and 'timely' diagnosis is helpful in this respect.¹³⁴ As the Alzheimer's Society noted in its response to our consultation: "for conveying a diagnosis to be helpful and appropriate, it must be timely, with benefits balanced against risks. Where a person stands to be distressed to the point where no benefit can be derived, then even an early diagnosis is perhaps not a timely one." This approach is in line with our own emphasis on considering both the well-being and the autonomy of the person with dementia: where the person is not seeking a diagnosis, and where their well-being is unlikely to be enhanced by the diagnosis, then it is inappropriate to force that diagnosis upon them.
- 3.17 However, while recognising this distinction between 'early' and 'timely' diagnosis, it is crucial not to make assumptions about the effect the diagnosis will have on the person with dementia. Recent research has suggested that the vast majority of people with mild dementia *do* wish to be informed about their diagnosis (even if family members think they do not), and that fears as to the impact of this information on the person's general mental health are generally unfounded.¹³⁵ It seems likely that a 'timely' diagnosis for most people will be the point when the cognitive and other changes they are experiencing begin to have a significant effect on their lives or on the lives of those close to them.
- 3.18 **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.** We welcome the fact that improvements in early intervention and diagnosis are highlighted in the Scottish dementia priority paper¹³⁶ and included as one of the seven "key priority

¹³² Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q6; Bamford C, Lamont S, Eccles M *et al.* (2004) Disclosing a diagnosis of dementia: a systematic review *International Journal of Geriatric Psychiatry* **19**(2): 151–69.

¹³³ Hansson O, Zetterberg H, Buchhave P *et al.* (2006) Association between CSF biomarkers and incipient Alzheimer's disease in patients with mild cognitive impairment: a follow up study *Lancet Neurology* **5**(3): 228–34.

¹³⁴ Alzheimer's Society, responding to the Working Party's consultation.

¹³⁵ See, for example, Carpenter BD, Xiong C, Porensky EK *et al.* (2008) Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment *Journal of the American Geriatrics Society* **56**: 405–12; Pinner G and Boulman WP (2003) Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis *International Psychogeriatrics* **15**(3): 279–88.

¹³⁶ NHS Scotland (2008) *Mental Health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government).

outcomes” in the English dementia strategy.¹³⁷ We caution, however, 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. As we note in Chapter 1 (see paragraph 1.36), there is no value at present in attempting to screen for the underlying disease processes in the brain before symptoms of dementia appear.

- 3.19 There is some evidence to suggest that people in some cultural groups may be more hesitant in coming forward for diagnosis than those from other cultural groups.¹³⁸ Although individual choices and differences should be respected, it is important, given the benefits of earlier diagnosis noted in paragraph 3.14, to understand the reasons that prevent people from coming forward. We suspect that feelings of shame and stigma associated with dementia (see Chapter 4) play an important part in these reasons and that their significance varies between cultures. There are also concerns as to potential cultural bias in some of the cognitive tests used in the process of diagnosing dementia.¹³⁹

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.

- 3.20 The way in which a diagnosis is conveyed is clearly also important and is a key aspect of demonstrating respect for the personhood and well-being of the person with dementia. Research published in 2008 highlighted the lack of sensitivity with which a diagnosis is sometimes conveyed, with participants in the research describing how they were treated in an uncaring and unsympathetic manner: being told “well it’s Alzheimer’s, what do you expect?”; or being given the diagnosis over the phone by someone they had never previously met.¹⁴⁰ It is also important that the disclosure of a diagnosis of dementia is not just seen as a one-off event, but rather as a *process*, starting with the point when the person is first referred for assessment and continuing on into follow-up support once the diagnosis itself has been established.¹⁴¹ We consider this issue of follow-up further below (see paragraphs 3.25–3.29).
- 3.21 Finally there is the question of to whom the diagnosis should be given: should close family members or other carers also be informed? Responses to our consultation included several examples where doctors assessed the person with suspected dementia but, on grounds of confidentiality, gave little or no information to relatives.¹⁴²
- 3.22 Whilst the principle of patient confidentiality is an important one in the doctor–patient relationship, a diagnosis of dementia has 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. Moreover, the assessment of possible early dementia requires information

¹³⁷ Department of Health (2009) *Living Well with Dementia: The national dementia strategy implementation plan* (London: Department of Health), paragraph 2.1.

¹³⁸ See, for example, La Fontaine J, Ahuja J, Bradbury NM, Phillips S and Oyebode JR (2007) Understanding dementia amongst people in minority ethnic and cultural groups *Journal of Advanced Nursing* **60**(6): 605–14.

¹³⁹ Rait G and Burns A (1998) Screening for depression and cognitive impairment in older people from ethnic minorities *Age and Ageing* **27**: 271–5; Shah A (1999) Difficulties experienced by a Gujarati geriatric psychiatrist in interviewing Gujarati elders in Gujarati *International Journal of Geriatric Psychiatry* **14**: 1072–4; Bowes A and Wilkinson H (2003) ‘We didn’t know it would get that bad’: South Asian experiences of dementia and the service response *Health and Social Care in the Community* **11**: 387–96.

¹⁴⁰ Alzheimer’s Society (2008) *Dementia: Out of the shadows* (London: Alzheimer’s Society), p22.

¹⁴¹ Fisk JD, Beattie BL, Donnelly M, Byszewski A and Molnar FJ (2007) Disclosure of the diagnosis of dementia *Alzheimer’s & Dementia* **3**: 404–10.

¹⁴² For example Agnes Charnley, responding to the Working Party’s consultation.

from those close to the person with possible dementia, both about their own awareness of changes in the person's behaviour and cognitive performance, and about any difficulties which family and friends are themselves experiencing. A person even in the early stages of dementia may not give an accurate account of what difficulties they or their family members face, and what care needs are present. This may be compounded by poor insight into the problems.

- 3.23 **We conclude that 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.** Practical ways in which professionals could promote information sharing in this way include encouraging the person to attend appointments with a friend or family member they trust, so that all information is given to both parties together; being willing to listen to those concerned about the person with dementia; and if necessary acting as an intermediary within the family.
- 3.24 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 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 (see further discussion of this issue at paragraphs 7.24–7.26). Professionals should also in such cases consider the issue of capacity very carefully, as inability to “understand the information relevant to the decision” (for example by being in denial over the diagnosis) may, under the Mental Capacity Act, mean that the person does not have legal capacity to make this decision. Nevertheless, it should be emphasised that both the Mental Capacity Act and the Adults with Incapacity (Scotland) Act protect a person's right to make unwise or risky decisions, as long as they retain the capacity to do so.

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.

Information, communication and signposting to services

“[The support needed most is] adequate provision of information ... relating to both the disease process itself, the diagnosis, the likely progression and prognosis, the treatment options and availability and access to care networks.” *British Geriatrics Society, consultation respondent*

“The support needed most is more advice strategies to deal with confusion and anxiety. I appreciate that everyone behaves differently but I do believe that there are common traits and it seems to be that every carer is learning the hard way from personal experience.” *Mrs Linda Tolson, consultation respondent*

Paul has been given a diagnosis of early dementia. He went to his GP, who asked him some questions and then sent him along to the local memory clinic. Here he saw a nurse and a doctor and had a few other tests done, including a brain scan. His wife, Marie, was there when he was given the diagnosis, which was helpful because he forgot quickly what the doctor said. The question now is what can be done? What support is available to him and also to Marie? What is likely to happen to him? How bad will the dementia get and how quickly? Who can help them navigate the implications of this difficult diagnosis? And what should he tell his children?

- 3.25 The importance of information, support and access to services immediately after diagnosis has been emphasised in a number of recent reports and guidelines, and was evident in the responses

we received to our public consultation.¹⁴³ Information that people find helpful includes factual information about particular forms of dementia, advice and counselling from professionals, tips on practical strategies for dealing with difficult situations or behaviours, and details about the availability both of peer support networks and other local statutory and voluntary services. Clearly, the information needs of any one person with dementia and those close to them will vary significantly, depending both on personal preference and on the nature and progress of their dementia at the point of diagnosis. A physically active person with early-onset dementia who is still in employment at the time of diagnosis is likely to have very different information and support needs compared with a much older person who already has some degree of community support from the NHS or social services because of existing physical health needs or general frailty.

- 3.26 There is, however, 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.¹⁴⁴ **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.**¹⁴⁵ We agree. We argue in Chapter 2 that people with dementia are of equal value to people without dementia, that their autonomy and well-being interests are important, and that some support may well be necessary in order to promote and protect those interests. It is clear from the reports cited above, the Department of Health's consultation on the English dementia strategy, and the responses to our own consultation, that 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.
- 3.27 People also need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services which people with dementia and their families may potentially use. Such support may take many forms, but we suggest that a key 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.**
- 3.28 Moreover, the importance of *communication* itself should not be underestimated. A common fear about dementia is the fear of being cut off from others, no longer able to communicate and relate to them in the way we have done in the past. An equally common misconception about dementia is the idea that, because spoken conversation becomes more difficult as the dementia progresses, communication itself becomes impossible. On the contrary, we believe that communication is indeed possible and that a key aspect of recognising and relating to the person with dementia is to find appropriate forms of communication through which they may be reached, however advanced their dementia may have become. Moreover, it has been argued that the extent to which decisions about people with dementia are likely to be right or good may depend on the extent to which communication between all concerned (the person with dementia, professionals, family and friends) is open, free and based on mutual respect.¹⁴⁶

¹⁴³ NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE); NHS Scotland (2008) *Mental health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government); Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q1.

¹⁴⁴ See, for example, National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), pp30–1; Alzheimer's Society (2008) *Dementia: Out of the shadows* (London: Alzheimer's Society), pp22–5.

¹⁴⁵ The Working Party's fact-finding meeting with people at the front-line of dementia care, 10 July 2008.

¹⁴⁶ Moody HR (1992) *Ethics in an Aging Society* (Baltimore: Johns Hopkins University Press).

3.29 The examples of practice outlined in Boxes 3.5–3.9 below illustrate what can be done in terms of information, advice and communication, to help people come to terms with their diagnosis, access the help and support they need, and continue to feel part of a social community.

Box 3.5: Example from practice – diagnosis and subsequent information and support

Newbury Memory Clinic, which is run in a GP surgery by the mental health trust old age psychiatry unit, offers holistic diagnosis and advice in the community. A diagnosis of dementia at the clinic is immediately followed by a meeting with the memory clinic nurse, who counsels the person with dementia and their carer and provides them with written information. They then meet with an adviser/counsellor from the clinic to inform them of a range of support networks and therapeutic activities.

Cited in: National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p29.

Box 3.6: Example from practice – post-diagnostic support system in the Stewartry area of Dumfries and Galloway

A partnership between **Alzheimer Scotland** and the **community mental health team (CMHT) in Dumfries and Galloway** provides early-stage support to people with a diagnosis of dementia, both through the provision of memory groups, and through personal support for people with dementia and their carers by a member of the CMHT. A key part of the programme is the use of a checklist, used at the person's own speed, which covers issues such as assessment, diagnosis, further information and explanation, medication, social impact, current support, carer assessment, challenging behaviour, relationship issues and welfare. Once all these issues have been 'ticked off' the list, the person with dementia and their carers should have a clear idea of where they can get help, if they need or want it. After this, there is continued support from the CMHT, from external agencies such as Alzheimer Scotland, and from social services, including access to a carer education and support course specifically aimed at carers 12–18 months after diagnosis.

More information from: Alzheimer Scotland, Dumfries and Galloway services, www.alzscot.org/pages/regions/dumfries.htm; telephone 01387 261303.

Box 3.7: Example from practice – psychological support and education for people with dementia and their families

Alzheimer Cafés provide a monthly gathering where persons with dementia and/or their family and friends can be together in a safe, welcoming environment, in the company of other carers, local Alzheimer support group members, volunteers, and health and social care professionals, for the purpose of emotional support, education and social interaction.

A typical evening at the Café starts with music and socialising over light refreshments. A presentation or interview about a theme linked with dementia then follows by a professional or family member with hands-on experience of the subject being discussed. The evening continues with further social interaction, refreshments and the opportunity to speak informally with the guest speaker or professionals present. Twice a year, purely social evenings are held with live music or other entertainment.

More information from: www.alzheimercafe.co.uk/What.htm.

Box 3.8: Example from practice – reaching people who might not otherwise access services

Bradford-based project '**Meri Yaadain**' raises awareness of dementia among Bradford's South Asian communities and encourages people with dementia and carers to access information, support and services. It includes a monthly support group with culturally appropriate activities and currently supports over 80 families, including providing advocacy support to ensure that local health and social services meet people's cultural and language needs.

More information from: www.alzheimers.org.uk/downloads/LWD_sep_08_low_res.pdf.

Box 3.9: Example from practice – good communication as speech becomes more difficult

Researchers at the **Augmentative and Alternative Communication (AAC) unit** at the University of Stirling have developed Talking Mats™, a low-technology communication framework for with people with dementia.

Talking Mats™ uses a textured mat and a system of simple picture symbols that are placed on the mat as conversation with a person with dementia progresses. Each picture offers the person with dementia the opportunity to express their feelings about four aspects of their well-being (activities; people; environment; and self) by placing the relevant image below a visual scale based on levels of happiness.¹⁴⁷

More information from: www.talkingmats.com/.

¹⁴⁷ Murphy J, Gray CM and Cox S (2007) *Communication and Dementia: How Talking Mats can help people with dementia to express themselves* (York: Joseph Rowntree Foundation), pp6–7; AAC Research Unit, University of Stirling, responding to the Working Party's consultation.

Ongoing care and support

“Practical assistance is only one part of the support required by a person with dementia. There is also a need for emotional happiness, stimulation and social interaction.” *Alzheimer’s Society, consultation respondent*

“Support must focus on enabling the person, and those around them, to sustain skills and to draw upon the strengths within their personality and previous experience.” *British Geriatrics Society, consultation respondent*

“Visiting a home for elderly people during my mental health block, I found that the home was more suited for people with a British background, from the décor, to the ballads from the 60s and 70s ... Would someone from a different culture really be able to enjoy themselves here?” *Member of the special study group on dementia, Leicester University, consultation respondent*

Roy is a 67-year-old man with mild multi-infarct dementia. He has been up and down quite a bit over the last few months, but generally copes well with the support of his partner, Doreen. He does tend to forget things, and every now and then can be a bit confused. Doreen and Roy have been together 20 years. Roy’s family have very little to do with him, but Doreen’s son and partner are very supportive of them both, popping round once or twice a week. The support is more emotional than practical, although they do take Roy and Doreen away with them on holiday every year. Derek, who is a member of a local voluntary care in the community organisation, goes out with Roy once or twice a week. They often go to the local football match, and, if the weather is good, fishing. This gives Doreen the time she needs to get the shopping and have her hair done, and Roy is able to continue with his lifelong interests. Derek will come round to stay with Roy when Doreen has to go out at other times, for example when she goes to her hospital appointment. Roy has got to know Derek well, and enjoys his company.

Winston is an 83-year-old man of West Indian origin. He was diagnosed with dementia four years ago, and the disorder has progressed quite rapidly. He needs a lot of help with self care, and with feeding. He needs escorting to the toilet. He currently lives with his 58-year-old daughter, Vanessa, and her partner. He attends a day centre two days a week. He also spends two weeks in residential care every three months, to give Vanessa time for a break, and give him a rest too. Vanessa has just picked her father up from a two-week stay in the care home, and been told that he seems to be off his food. He has been seen by the doctor, and there does not appear to be any physical cause for this. When Vanessa gets him home, he seems to regain his usual very good appetite. She wonders what has been going on. Is he unhappy in the home? Is it because the staff at the home seem to have changed again? Or does he just like her cooking? She does tend to make him some of his favourite West Indian dishes. Or might it be that he enjoys meal times where she spends a long time with him helping him to eat his food in a quiet environment?

- 3.30 We have stressed the importance, if care is to be of appropriately high ethical standards, of support that promotes the autonomy and well-being of the person with dementia and that recognises their individuality and value as a person. NICE has made a number of recommendations in these areas, emphasising the importance of promoting independence and helping maintain a person’s skills, responding flexibly to fluctuating abilities, providing care in a stable and familiar environment, and enabling the person to participate in activities which they enjoy. The English dementia strategy similarly stresses the importance of community personal support services “ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of broader family circumstances.”¹⁴⁸ The strategy further highlights the role of housing and housing support services in supporting people with dementia to live in their own homes for as long as possible, and the importance of ensuring people are able to ‘live well’ with dementia in care homes.¹⁴⁹
- 3.31 **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.**

¹⁴⁸ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health), p46.

¹⁴⁹ *Ibid*, pp55–61.

Clearly, the development of a particular level of high-quality services will be dependent in part on resources, both in terms of money and in terms of a workforce with the appropriate skills and, as we discuss in Chapter 4 (see paragraph 4.38), we hesitate to make specific recommendations with economic implications which we are not well placed to consider. However, 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. Some people who have difficulty doing their own shopping, for example, may prefer to go shopping with a home care worker, rather than having the shopping done for them.¹⁵⁰ Similarly, in some cases where the person with dementia needs more intimate personal care in the home, in terms of washing, dressing and using the toilet, but has a carer able and willing to provide this support, the person and their family may best be supported by offering other forms of assistance instead of insisting that only personal care is available. Responding to need with this degree of flexibility does not necessarily involve increasing budgets, or making difficult trade-offs between the needs of one group and the needs of another.

Box 3.10: Example from practice – ‘In control’ approach in East Renfrewshire

Alzheimer Scotland is launching a new post-diagnosis project in East Renfrewshire and Renfrewshire. Supported by the Scottish Government, the project will help people with early dementia to come to terms with their diagnosis, and will support them to find their own ways of maintaining their network and natural supports instead of being offered a single package of ‘care’. The project will also support people to use ‘advanced person-centred planning’ to design future support using individual budgets over which they have personal control.

More information: www.alzscot.org/downloads/dis65.pdf.

3.32 We also highlight the high value to be placed upon developing relationships with individual care workers, particularly those working in the person’s own home. In one of our fact-finding meetings, for example, we heard of one person with dementia who received home care from 14 different people over a period of eight months.¹⁵¹ While some degree of staff turnover is inevitable, examples such as these suggest that the importance to the person with dementia of personal relationships, particularly where intimate care is being provided, has been given little consideration or priority in the planning of some services. Indeed, there is some evidence to suggest that support for home care workers – such as regular meetings with other team members where information can be shared and discussed – and access to training, may make it easier for services to retain their staff.¹⁵² Such support for staff not only acknowledges the importance of the interests of staff being given weight for their own sake (see paragraph 2.42), but is also likely to have a positive effect on the autonomy and well-being of the person with dementia.

3.33 As we discuss above (see paragraph 3.5), the ‘small things’ of care are extremely important in ensuring that care is genuinely supportive of the individual, and enhances a 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. We note in Box 3.13 below some examples of how these ‘small things’ may be achieved in practice.

¹⁵⁰ Snayde F and Moriarty J (2009) Person-centred home-care for people with dementia: developing a specialist service in an ethnically diverse community *Dementia* 8(1): 148–52.

¹⁵¹ The Working Party’s fact-finding meeting with people at the front-line of dementia care, 10 July 2008.

¹⁵² Snayde F and Moriarty J (2009) Person-centred home-care for people with dementia: developing a specialist service in an ethnically diverse community *Dementia* 8(1): 148–52. See also Vernooij-Dassen MJ, Faber MJ and Olde Rikkert MG (2009) Dementia care and labour market: the role of job satisfaction *Aging & Mental Health* 13(3): 383–90.

- 3.34 In Chapter 2 we suggested that the idea of treating a person with dignity can be helpful in the setting of dementia care and this is perhaps particularly true with regard to helping people with their personal and physical care needs. When people complain that a person with dementia has been treated in an undignified manner, it is often with respect to some aspect of physical care such as toileting or dressing; or the way in which a person is spoken to authoritatively or patronisingly, or alternatively left alone and ignored. The concept of dignity is useful, we believe, in highlighting both the autonomy and well-being of the person with dementia. If a person with dementia is neither able to express how they would like to be treated, nor to complain about how they are being treated, then it may be difficult to judge what should be done. The concept of dignity can be helpful in highlighting that it remains important, even in very severe dementia, to think carefully about the interests and feelings of the person. Treating a person with dignity involves a compassionate understanding of what the person is likely to be experiencing, and respecting the views and values that they previously held.
- 3.35 The notion of treating a person with dignity can thus be helpful in ensuring that a person is not ignored or left in an inappropriate state. But thought still needs to be given to what is meant by 'dignity' in a particular situation, and this involves, in our view, careful consideration of both a person's autonomy and their well-being. For example, a person with dementia in a care home who tends to remain in their own bedroom may in some cases be actively choosing privacy, but in others they may remain there simply because they cannot remember where they are, or how to find the lounge without becoming lost and distressed. Similar difficulties may arise in helping a person with their choice of clothes: is the goal to make the person look normal or dress in their characteristic way, or to help them be comfortable, or to let them choose for themselves even at the risk that their choices may make them conspicuous or provoke criticism? Although there is no straightforward answer to these questions, the idea of dignity alone seems insufficient. Some balancing of various interests – the person's previous views, current wishes, and well-being interests – is needed in this situation.

Box 3.11: Example from practice – support in everyday activities

"I was put in touch with Neil, a befriender. We meet twice a week. We have a good understanding and trust one another. Our meetings are good fun. Neil doesn't tell me where to go – I ask and he takes me. He'd never been fishing but he took it up to please me. I'd never been bowling, so he took me."

JDI Mutual Support Group (2008) *In the Mists of Memory — A celebration of the circle of life* (Falkirk: Joint Dementia Initiative), p47.

Box 3.12: Example from practice – support in the community

Guideposts Trust Specialist Dementia Home Care Service has been developed with Warwickshire Social Services to provide a specialist, needs-led and person-centred dementia domiciliary service. It:

- provides support within people's own homes;
- enables people with dementia to maximise their lives through identifying their strengths and abilities; and
- facilitates hospital discharge, helping people remain in their own homes and reducing unnecessary admission to 24-hour residential care.

Guideposts Dementia Home Care Service, telephone: 01788 577825. See: www.guidepoststrust.org.uk/warwickshire/index.php?page=specialist_dementia.

Dementia Care Partnership (DCP) is a charity based in Newcastle-upon-Tyne. Formerly the Dementia Care Initiative, it provides local services for people with dementia and their carers. DCP aims to offer community-based alternatives to residential care. It offers people with dementia and their carers services such as home support, day activity centres, supported-living houses in partnership with social and housing services, a 24-hour companion and befriender scheme, and residential short term breaks.

DCP has also established The Bradbury Centre, a facility for people with dementia and their carers (and also open to the general public) that incorporates services such as a café, a hairdresser, a health and fitness room, a multi-faith room, and a training and conference facility.

Dementia Care Partnership: www.dementiacare.org.uk/html/about_us.html. See also Garwood S (2009) Partnership in word and deed *Journal of Dementia Care* 17(1): 20–4.

Box 3.13: Example from practice – residential care

Vale House in Oxford is a purpose-built specialist care home, caring for 20 people with dementia. The admission criteria are that the person has dementia, is (usually) over 60 years old, and has behavioural difficulties (such as very loud or aggressive behaviour) which cannot be managed elsewhere. The philosophy of the home (described by the Head of Home as ‘the reason why we’re doing this’) includes:

- respecting the ‘adult status’ of the person with dementia;
- helping people with dementia live their lives as independently as possible, making full use of their remaining capacities;
- recognising that feelings matter every moment of the day;
- focusing on providing comfort and support; and
- acting in a ‘person-centred way’ to colleagues as well as residents.

Important aspects of living up to this philosophy include finding out as much as possible about the person with dementia before they move into the home, training staff to be very aware of the importance of ‘little things’ like smiling and talking softly, and liaising closely with families.

Vale House, Oxford: www.valehouse.org.uk.

Box 3.14: Example from practice – dementia-specific design in residential care

A range of visuoperceptual and orientation difficulties often occur in dementia, in addition to normal visual difficulties associated with age. Ideas such as those below are increasingly being promoted:

For care:

- Help with activities and socialisation: for example adapting the layout of communal rooms into smaller, social groupings, so that people can see and hear each other better; providing a variety of types of seating to suit a person’s choice of activity; and providing alternatives to constant television, such as an aquarium or calming DVD images.
- Ensuring that residents are not startled when staff approach them – for example by approaching from the front, or speaking first.
- Use of strong colours for crockery and cups: in one study, a group of people with advanced Alzheimer’s disease ate nearly 25 per cent more than usual when offered meals on bright red crockery and drank over 80 per cent more than usual when offered drinks in bright red cups, compared with the original white.¹⁵³

For more appropriate environments:

- Appropriate use of bright and strongly contrasting colours to highlight important features such as toilet doors, toilet seats, handrails and steps.
- Provision of good levels of lighting to eliminate shadows and promote mobility.
- Use of colour and design to encourage orientation, for example using different colours, or particular types of artwork, to identify different parts of the building.
- Avoiding use of reflective surfaces and mirrors which may easily be misinterpreted, and strongly patterned surfaces.

For more information on design recommendation, see Jones GMM and van der Eerden WJ (2008) Designing care environments for persons with Alzheimer’s disease: visuoperceptual considerations *Reviews in Clinical Gerontology* 18: 13–37. The Dementia Services Development at Stirling University has developed a gold standard award scheme for dementia-friendly design, with the first award made in 2008 to The Lodge (dementia care facility) at Buckshaw Retirement Village.

Box 3.15: Example from practice – services for people with learning disabilities and dementia

Bourne Cottage in Ewell, Surrey, is a specialist day service run by Surrey Council’s adult social care department for people with dementia and learning disabilities. The cottage is open on a daily basis to people with learning disabilities and dementia who have become distressed when attending their usual, busier day services.

The cottage hosts around ten people with learning disabilities and dementia each day, offering facilities such as a sensory garden and opportunities to participate in reminiscence activities in a comfortable, manageable environment. Although the cottage welcomes carers of those who visit the cottage, they are not obliged to accompany the person for whom they care.

More information: Dr Karen Dodd, Surrey and Borders Partnership NHS Foundation Trust (drkaren.dodd@sabp.nhs.uk).

Box 3.16: Example from practice – enhancing lives

Music for Life is a partnership between the organisation ‘for dementia’ and **Wigmore Hall**. The project works with people with dementia and the staff who care for them in a variety of settings. Professional musicians use improvisation to draw out the potential of people with dementia for self-expression and communication, particularly helping those who are emotionally isolated and disempowered as a result of the advanced stage of their condition.

More information: www.wigmore-hall.org.uk/community-and-education/musicforlife and www.fordementia.org.uk.

¹⁵³ Dunne T, Neargarder S, Cipolloni P and Cronin-Golomb A (2004) Visual contrast enhances food and liquid intake in advanced Alzheimer’s disease *Clinical Nutrition* 23(4): 533–8.

Acute hospital services

“My mother became bed-bound for a few weeks on going into hospital. Physiotherapy was arranged to help to get her mobile again. She was denied help because no one could give her any physical support, so no one could help her out of her chair, and also because she was in some pain, and said ‘no’. She never walked again.” *Anonymous consultation respondent*

“... A patient with dementia who is admitted to an acute ward following an infection or fall finds themselves being repeatedly transferred from one ward to another, and from one bed to another ... The hospital then express surprise or outrage when the patient who has been moved around like a parcel becomes frightened and protests loudly, or gets into the wrong bed by mistake.” *Anonymous consultation respondent*

Farah is 78 years old. She has Alzheimer's disease, and is currently living in a residential home. She copes very well but does have a tendency to 'wander'. Her daughter, Priya, lives nearby and visits two or three times a week. The rest of the family live further away. Farah has a possible skin cancer on her arm that needs to be removed. However, she is likely to get confused by the trip to the hospital. Priya is concerned as her last trip with her mother to the hospital, following a fall in which she fractured her wrist, was not a good one. Her mother became very agitated during the three-hour wait to be seen in casualty and the staff did not know how to deal with her behaviour.

- 3.36 People with dementia often require medical assessment, services and treatment that are not directly related to their dementia: for example, they may need to attend an accident and emergency department after a fall, or be admitted into hospital for an orthopaedic operation or for treatment of a serious infection. Respondents to our consultation gave examples of difficulties that people with dementia and carers sometimes experience through lack of knowledge on the part of some health professionals about dementia, and also through lack of arrangements in hospitals for enabling people with dementia to be properly assessed and treated for these independent medical conditions. For example, hospital staff sometimes interpreted behaviour linked with the dementia, such as wandering off, as evidence that the person was refusing or avoiding assessment, with the result that proper assessments were not carried out; or hospitals were inflexible in not understanding or allowing for the problems of fear and confusion that can be particularly problematic for people with dementia, for example by not allowing relatives to stay with the person with dementia.¹⁵⁴
- 3.37 Not only do such experiences cause significant (and often avoidable) distress at the time to people with dementia and their carers: there is also evidence to suggest that the disorientation and distress that people with dementia often experience in hospital have a long-term and permanent effect on the person's cognitive abilities and capacity to continue coping on their own.¹⁵⁵ Indeed, a hospital admission will often be a 'trigger' for admission into residential care, thus forcing the person with dementia and those close to them to make important decisions about the future at a point of crisis, instead of in their own time.¹⁵⁶
- 3.38 Although there were accounts of problems, we also came across areas of good practice and we describe some of these in Boxes 3.17 and 3.18 below. As we note at the beginning of this Chapter (see paragraph 3.1), there may be good reasons why an innovative solution that works well in one area may not simply transfer elsewhere, and more research comparing different models for supporting people with dementia appropriately in hospital is needed (see Recommendation 16

¹⁵⁴ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q21.

¹⁵⁵ Borbasi S, Jones J, Lockwood C and Emden C (2006) Health professionals' perspectives of providing care to people with dementia in the acute setting: toward better practice *Geriatric Nursing* 27(5): 300–8.

¹⁵⁶ See, for example, Ballard C, Clack H and Green D (2007) Postoperative cognitive decline, dementia and anaesthesia *British Journal of Hospital Medicine* 68(11): 576–7; Holmes J and House A (2000) Psychiatric illness predicts poor outcome after surgery for hip fracture: a prospective cohort study *Psychological Medicine* 30: 921–9.

after paragraph 8.18). The English dementia strategy promotes the idea of specialist liaison older people's mental health teams in general hospitals, but notes that there is considerable diversity in the models currently adopted and highlights the need for a thorough review of the evidence base.¹⁵⁷ It seems to us that, whatever model of support is chosen, there will be at least two features which will be essential to its success: first, staff who are knowledgeable about dementia; and, secondly, an underpinning belief that people with dementia are fully 'persons' who are entitled to the same level of good medical care as anyone else.

Box 3.17: Example from practice – providing support in A&E

The Accident and Emergency Department at **Southampton University Hospitals NHS Trust** includes a team providing specialist assistance to people with dementia. The team aims to identify people with dementia (with or without a diagnosis) who attend A&E for reasons such as a fall. They are able to offer a quiet space within the A&E department to take histories from both the person with dementia and their carer, allowing as much time as is necessary. They are then able to make direct contact with relevant services such as community services, GPs, equipment stores and Community Mental Health Teams, in order to avoid inappropriate admissions, while recognising that in some cases admissions will be appropriate.

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Box 3.18: Example from practice – specialist GP support to care homes

Dr Gillie Evans works as a GP at the **Jenner Health Centre** in Whittlesey, Cambridgeshire. She provides dedicated GP services to 50 residents with moderate and severe dementia living in a care home in her local area.

Since 2002, Dr Evans has taken a personal list approach to the care of these residents, visiting on a weekly basis for a full morning session. She is supported in this approach by the home manager and all the staff. A member of the nursing staff accompanies her and communicates with relatives after her visit.

More information from: www.dementia.jennerhealthcentre.co.uk/.

End of life palliative care

“... we know people with dementia can be deprived of even basic palliative care.”

Admiral Nurses – ‘for dementia’, consultation respondent

John has severe dementia. In his working life he managed a large department in a production factory, doing a great deal of national and international travel. Control and personal autonomy were very important to him. In conversations about the end of life with his family he said that if he were to become a 'cabbage' the family were to 'switch the machine off'. Yet, once he began to be affected by dementia, he found things to enjoy, particularly his family and grandchildren. Now, although confined to bed and having to be turned regularly to prevent bed sores, he still remains at home cared for by his wife, district nurses and care workers. His life is in its end stages. He appears to be comfortable and not in pain, and seems to enjoy familiar faces. Yet, in the near future there may be difficult decisions to face. What should be done if he gets a chest infection? Should he be admitted to hospital, which is the last thing his wife would want? What should happen when he can no longer take the food so lovingly prepared for him? Should he be fed by a tube? How can he best be cared for at this stage of his life? How can the values of promoting his interests, respecting his personhood, and even at this stage enabling him to live a life as little restricted by the disease as possible, guide the provision of his care?

3.39 NICE has recommended that a palliative care approach, considering a person's "physical, psychological, social and spiritual needs", should be adopted from diagnosis to death, and that people with dementia should have the same access to palliative care services as others.¹⁵⁸ The importance of access to appropriate end of life care for people with dementia has also been emphasised in the English dementia strategy, the Scottish dementia priority paper and the draft

¹⁵⁷ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health), p53.

¹⁵⁸ NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE), paragraph 1.10.

action plan for Wales,¹⁵⁹ and in the English and Scottish end of life strategies.¹⁶⁰ We have already discussed in paragraphs 3.8 and 3.9 how the concept of ‘supportive care’ seeks to avoid a sharp distinction between ‘active treatment’ and ‘palliative care’ by emphasising the individual’s need for ongoing physical, psychological, social and spiritual care, regardless of the existence (or absence) of any form of therapy targeted at the underlying disease. In this section, we will therefore use the term ‘palliative care’ to refer to the specific care needs which arise at the very end of life. As such, it can be regarded as one component of supportive care.

- 3.40 As the recommendation from the NICE/SCIE guidelines, cited above, implies, there is a growing awareness of the inadequacy of current palliative care support for people with dementia, and the need to take action to ensure that appropriate services become available. It should be noted that, at present, there is only limited evidence for the effectiveness of traditional palliative care models in dementia.¹⁶¹ It may be harder to identify when the person with dementia is truly reaching the end of their life;¹⁶² some of the skills involved in providing specialist end of life care to people with dementia may differ from those developed in the context of cancer;¹⁶³ moreover, as many people with dementia will already have moved from their own homes into a care home,¹⁶⁴ a further move into the new environment of a hospice would not usually be appropriate.
- 3.41 Nevertheless, there *is* evidence that people with dementia experience poor care at the end of their lives, with badly controlled pain, little control over the place and manner of their death, and significant stress on their carers.¹⁶⁵ Moreover, recent research in the UK has suggested that amongst older people who die in hospital, those who have dementia are less likely to receive palliative medication, are less likely to have attention paid to their spiritual needs, and are less likely to be referred to palliative care specialists than people who do not have dementia.¹⁶⁶
- 3.42 There is further concern that many people with dementia are fed inappropriately through a tube at the end of their lives, without proper consideration being given as to possible alternatives or to the effect on the individual. The National Council for Palliative Care, for example, highlights that current evidence supports “careful hand feeding” as being the feeding method of choice for people with advanced dementia, especially given the benefits of additional human contact and social interaction; and encourages those considering tube feeding to think carefully in each case about what it is that they are hoping to achieve, given the terminal nature of end-stage dementia;

¹⁵⁹ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health); NHS Scotland (2008) *Mental Health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government); Welsh Assembly Government (2009) *National Dementia Action Plan for Wales, Consultation Draft* (Cardiff: Department for Health and Social Services).

¹⁶⁰ NHS Scotland (2008) *Living and Dying Well: A national action plan for palliative end of life care in Scotland* (Edinburgh: The Scottish Government); 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).

¹⁶¹ Sampson EL, Ritchie CW, Lai R, Raven PW and Blanchard MR (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia *International Psychogeriatrics* **17**(1): 31–40.

¹⁶² National Council for Palliative Care (2008) *Creative Partnerships: Improving quality of life at the end of life for people with dementia – a compendium* (London: National Council for Palliative Care), p23.

¹⁶³ National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care), p8, citing, for example, skills in communicating with people with advanced dementia and managing difficult behaviours.

¹⁶⁴ McCarthy M, Addington-Hall J and Altmann D (1997) The experience of dying with dementia: a retrospective study *International Journal of Geriatric Psychiatry* **12**: 404–9.

¹⁶⁵ See, for example, Sampson EL, Gould V, Lee D and Blanchard MR (2006) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study *Age and Ageing* **35**: 187–9; Addington-Hall J, Fakhoury W and McCarthy M (1998) Specialist palliative care in non-malignant disease *Palliative Medicine* **12**(6): 417–27; National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care).

¹⁶⁶ Sampson EL, Gould V, Lee D and Blanchard MR (2006) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study *Age and Ageing* **35**: 187–9.

what the person would have wanted; and what action would genuinely be in the person's best interests.¹⁶⁷ This issue was picked up in the English dementia strategy, which cited a 2004 report of people with dementia dying "with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care", as an example of the need for significant improvement.¹⁶⁸

- 3.43 It is clearly imperative that key elements of the palliative care approach – in particular the focus on caring for the 'whole person', the importance of advance care planning (see Chapter 5), the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family – should be made available in an appropriate way to people who are dying with dementia. One reason put forward as to why people with dementia have traditionally not been able to access hospice care is the simple fear that including people with dementia might overwhelm existing services or make them unaffordable.¹⁶⁹ While this concern may be quite understandable at the level of individual small services struggling to survive on charitable funding, such an attitude within the wider NHS is completely inconsistent with the equal value to be placed on people with dementia and the importance to be placed on consideration of their interests.
- 3.44 As the 2008 National Audit Office report on end of life care makes clear, palliative care services are increasingly being delivered in a variety of environments outside hospices, including in hospitals, care homes and people's own homes, with palliative care specialists working in partnerships with other health and social care professionals such as GPs and district nurses.¹⁷⁰ It seems highly likely that 'partnership working' of this kind will be the way forward to ensuring that the benefits of specialist palliative care are made available to people with dementia and their families. Indeed, in January 2008 and again in February 2009, the National Council for Palliative Care published practical guidance on developing partnership-based approaches to palliative care for people with dementia, based on a number of case studies and commentaries by professionals from different disciplines.¹⁷¹ Examples cited include the 'Croydon project', where specialists from St. Christopher's Hospice in London provide both training and supervision within nursing homes to enable nursing home staff to develop palliative care skills; and a partnership between 'Housing 21' supported housing and Macmillan nurses to provide end of life care to a woman with dementia who also had terminal liver cancer and wished to remain in her own extra-care home. In Scotland, the 'Beyond Barriers' project has similarly sought to develop current care practice in care homes by supporting both staff and relatives to meet the palliative care needs of people in the later stages of dementia.¹⁷²
- 3.45 **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. We also strongly agree with the National Council for Palliative Care that close working locally between**

¹⁶⁷ National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care), pp19–20.

¹⁶⁸ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health), p63.

¹⁶⁹ National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care), p8.

¹⁷⁰ National Audit Office (2008) *End of Life Care* (Norwich: The Stationery Office).

¹⁷¹ National Council for Palliative Care (2008) *Creative Partnerships: Improving quality of life at the end of life for people with dementia – a compendium* (London: National Council for Palliative Care); National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care).

¹⁷² Alzheimer Scotland (2009) *Beyond Barriers: Developing a palliative care approach for people in the later stages of dementia – an Alzheimer Scotland partnership project* (Edinburgh: Alzheimer Scotland).

those responsible for dementia care and those responsible for end of life care is absolutely crucial: neither will be fully effective without the other.¹⁷³

- 3.46 An inevitable aspect of end of life care concerns decisions as to when it may be appropriate *not* to provide a particular treatment for the dying person and how best to manage symptoms, particularly pain, at the very end of life. Such decisions are often difficult, even when there is no real clinical doubt as to the appropriateness of the decision. Staff at the specialist dementia home Vale House, for example, cited the situation when a person with dementia definitively stops eating, and where attempts to encourage continued eating fail, as a particularly difficult ethical dilemma, even though in such circumstances it is widely accepted that tube feeding is not appropriate, and death is inevitable.¹⁷⁴ Professional guidance and literature in this area draw a distinction between feeding difficulties because of dementia, which require a gentle and largely palliative approach, and feeding difficulties caused by other illnesses affecting the person with dementia, which may sometimes require short-term artificial nutritional support.¹⁷⁵
- 3.47 We discuss in more detail in Chapter 5 how a person's earlier wishes and decisions about their health care should be considered and balanced with any preferences conveyed (for example through behaviour or gesture) after the person has lost the legal capacity to make such decisions. We note here, however, that our focus on the value of the person with dementia, and the importance of both their autonomy and their well-being, make very clear that a decision to cease active treatment (for example withholding antibiotics that may possibly cure a chest infection) should not be made on the premise that a life with dementia is not worth living. Rather, in such cases, the benefits and burdens of treatment for *this* particular person must be considered.¹⁷⁶

Box 3.19: Example from practice – enabling people to die at home

In an article published in the *British Medical Journal*,¹⁷⁷ Tim Dartington recounts how Anna, his wife, having been given a diagnosis of Alzheimer's disease, was able to die at home.

Tim was encouraged to write an advance care plan for Anna by her care manager. The plan specified that the intention was to nurse Anna in the family home in the last stages of her illness, as she would have wished. With the support of an Admiral nurse and a palliative care consultant, and the foresight to write an advance care plan, Tim was able to be with Anna "at home when she finally stopped breathing."¹⁷⁸

Box 3.20: Example from practice – enabling people to die in a care home – Sue Ryder Care

Sue Ryder Neurological Care Centres have set up a programme called Palliative Initiatives in Neurological Care (PINC). PINC has adapted and piloted the three nationally recognised end of life care tools (Gold Standards Framework in Care Homes, Liverpool Care Pathway and Preferred Priorities for Care), and aims to help more residents die in the care setting of their choice, through providing palliative care education and training to Sue Ryder care staff. It also aims to reduce the number of residents who are moved inappropriately to hospital in the last weeks of their life.

More information: www.endoflifecareforadults.nhs.uk/eolc/ssuer.htm.

¹⁷³ National Council for Palliative Care (2009) *Out of the Shadows: End of life care for people with dementia* (London: National Council for Palliative Care), p4.

¹⁷⁴ Working Party fact-finding meeting with Vale House, 30 Sept 2008; NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE), paragraph 1.10.1.4.

¹⁷⁵ Kindell J (2002) *Feeding and swallowing disorders in dementia* (Bicester, UK: Speechmark Publishing Ltd); NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, NICE Clinical Guideline 42 (London: NICE and SCIE), paragraph 1.10.1.4.

¹⁷⁶ See also General Medical Council (2009) *End of Life Treatment and Care: Good practice in decision-making – a draft for consultation* (London: General Medical Council).

¹⁷⁷ Dartington T (2008) Dying from dementia: a patient's journey *British Medical Journal* 337: 931–3.

¹⁷⁸ *Ibid*, 933.