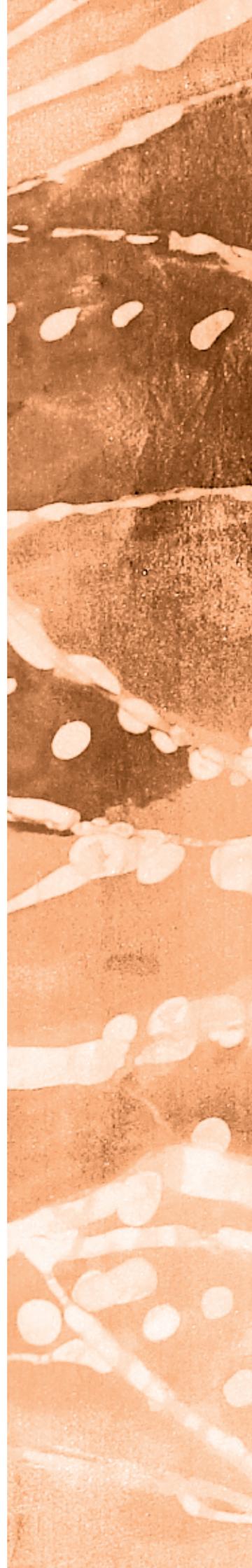


Chapter 4

Dementia and society



Chapter 4 – Dementia and society

Public perceptions of dementia

“Even care homes registered for dementia can display remarkable ignorance. I have had families ring to inquire about a room for someone with dementia to be told ‘we’ll take dementia but not Alzheimer’s.’” Mrs Lesley Perrins, consultation respondent

“Alzheimer Scotland is doing some useful work in schools so that children will not be afraid if their grannies or granddads have the illness.” Jan Lethbridge, consultation respondent

- 4.1 Dementia is a widely-feared condition, with surveys suggesting that older people, in particular, are more concerned about the possibility of their developing dementia than they are about cancer, heart disease or stroke.¹⁷⁹ It has also traditionally been a taboo subject: in the past people have often been unwilling to acknowledge publicly that a family member had been diagnosed with the condition, or even talk generally about the condition.¹⁸⁰
- 4.2 This public silence is beginning to change. There has been considerable press coverage in recent years both of the likely impact, social and financial, of increasing levels of dementia as the population ages, and of the implications for individuals with a diagnosis of dementia. Popular drama series on radio and television have included storylines about dementia. There is regular press coverage about standards of care in care homes, and of the experiences of families in caring for a person with dementia, although bad experiences tend to be seen as more newsworthy than good ones.¹⁸¹ Well-known people such as Terry Pratchett have done much to publicise dementia by being prepared to talk publicly about their own diagnosis, feelings and experiences.¹⁸² It was also striking that, in our own public deliberative event involving over 50 people with no prior specialist knowledge of dementia, participants commented that people usually felt uncomfortable talking about dementia, yet were not at all inhibited about taking full part in the discussion in the context of our event.¹⁸³ This suggested that the remaining taboos may be relatively thin if tackled openly.
- 4.3 However, it is clear that, although the word ‘dementia’ is no longer unspoken, it still carries different connotations from most other disorders. As the English Health Secretary, Alan Johnson, pointed out in October 2008, there are parallels with how cancer was regarded in the 1970s: “Thirty years ago, despite its considerable prevalence, cancer was seen as a taboo – an illness that wasn’t talked about in polite society and was inevitably fatal ... Dementia carries the stigma today

¹⁷⁹ See, for example, MetLife Foundation (2006) *Alzheimer’s Survey: What America thinks* (New York: MetLife Foundation); Alzheimer’s Research Trust (2008) *Dementia: YouGov survey results* (Cambridge: Alzheimer’s Research Trust; London: YouGov): in both surveys respondents aged 55 and above said they feared dementia more than cancer, stroke and heart disease. Among younger people, however, cancer was still feared more than dementia.

¹⁸⁰ See, for example, Corner L and Bond J (2004) Being at risk of dementia: fears and anxieties of older adults *Journal of Aging Studies* 18: 143–55; the criticism of Carol Thatcher when she made public the fact that her mother had developed dementia (see, for example, Pierce A (2008) Carol Thatcher’s candour goes too far *Telegraph*, 30 August, available at: www.telegraph.co.uk/comment/columnists/andrewpierce/3561792/Carol-Thatchers-candour-goes-too-far.html); and the initial comments of those taking part in our public deliberative event summarised in Opinion Leader (2008) *Deliberative Workshop on Dementia: A report prepared for the Nuffield Council on Bioethics* (London: Opinion Leader), p11.

¹⁸¹ See, for example, Daily Mail (8 Dec 2008) *Alzheimer’s has made my lovely husband so violent I can’t look after him. Why won’t the NHS help?*, available at: www.dailymail.co.uk/health/article-1093003/Alzheimers-lovely-husband-violent-I-look--Why-wont-NHS-help.html; The Guardian (17 Mar 2009) *Thousands of dementia patients cared for by untrained staff*, available at: www.guardian.co.uk/society/2009/mar/17/dementia-care-homes; The Telegraph (9 Apr 2009) *Elderly home care patients subjected to shocking neglect – investigation*, available at: www.telegraph.co.uk/health/elderhealth/5124881/Elderly-home-care-patients-subjected-to-shocking-neglect--investigation.html.

¹⁸² See, for example, Alzheimer’s Research Trust press release (2008) *Brown meets Pratchett, pledges to rethink funding for Alzheimer’s* 26 Nov, available at: www.alzheimers-research.org.uk/news/article.php?type=Press&archive=0&id=326.

¹⁸³ Opinion Leader (2008) *Deliberative Workshop on Dementia: A report prepared for the Nuffield Council on Bioethics* (London: Opinion Leader), p11.

that cancer no longer does.”¹⁸⁴ Moreover, although reference to dementia in the public domain is now much more common, it does not follow that general understanding of dementia has also improved. In our public deliberative event, it was clear that while people had a broad awareness of the condition and some of the better-known symptoms, they knew little about the causes of the condition, its impact on people’s lives and how the disease progresses.¹⁸⁵

4.4 This combination of good general awareness of the existence of dementia but poor detailed understanding of its causes, progression and implications tends to lead to inaccurate assumptions about the lives and experiences of people with dementia. Such assumptions may serve either to underestimate the effect on the person and the kind of support required – “it’s only about not remembering things”¹⁸⁶ – or may encourage wildly inaccurate perceptions about how a person with dementia will behave – “they all get violent, don’t they?”¹⁸⁷ There is also little understanding that dementia is a medical disorder and that the symptoms of dementia are the result of physical damage to the brain.

4.5 It is clear that, despite some lessening of the taboos around dementia, and increasing discussion within the media, the general perception both of dementia as a condition and of the lives of people with dementia is overwhelmingly negative. As one respondent put it:

“[There is] a very negative perception of dementia, equating it with decay, shabbiness, and ultimately horror. I say this while reflecting on the response of everyone from taxi-drivers to relatives when I tell them that I am a professor in this subject. People agonise over whether there is a more attractive set of words to describe what happens in my building. But it is getting better.” *Professor June Andrews, Director, Dementia Services Development Centre, University of Stirling, consultation respondent*

4.6 At first sight the observation that general impressions of dementia are essentially negative may seem trite: to quote the Joseph Rowntree Foundation, dementia is “not a lifestyle of choice.”¹⁸⁸ And yet, we have already highlighted our belief that a good quality of life with dementia is possible, for much of the time, and we have noted how people with relatively early-stage dementia have themselves made public how, despite the very serious nature of their diagnosis, they have succeeded in creating something positive for themselves out of their lives.¹⁸⁹

Stigma

“And whereas no one would trivialise the symptoms of cancer, dementia is an easy target – it is not unknown for people to refer to a dementia sufferer as ‘a bit doolally’, or ‘away with the fairies’.” *Speech by Alan Johnson, Secretary of State for Health, 24 October 2008*¹⁹⁰

“Stigma by proxy is experienced by the workforce caring for people with dementia ... often these roles are not valued in terms of pay.” *Admiral Nurses – ‘for dementia’, consultation respondent*

¹⁸⁴ Department of Health (2008) *Speech by Rt Hon Alan Johnson MP, Secretary of State for Health, National Children and Adult Services Conference, 24 October 2008*, available at: www.dh.gov.uk/en/News/Speeches/DH_089682.

¹⁸⁵ Opinion Leader (2008) *Deliberative Workshop on Dementia: Executive summary* (London: Opinion Leader), p3.

¹⁸⁶ Mrs Lesley Perrins, responding to the Working Party’s consultation, highlighting the inaccuracy of this view.

¹⁸⁷ *Ibid.*

¹⁸⁸ Joseph Rowntree Foundation, responding to the Working Party’s consultation.

¹⁸⁹ See, for example, Joint Dementia Initiative Mutual Support Group (2008) *In the Mists of Memory: A celebration of the circle of life* (Falkirk: Joint Dementia Initiative).

¹⁹⁰ Department of Health (2008) *Speech by Rt Hon Alan Johnson MP, Secretary of State for Health, National Children and Adult Services Conference, 24 October 2008*, available at: www.dh.gov.uk/en/News/Speeches/DH_089682.

“In my experience people have always shown great consideration and compassion towards my wife. This may be partly because in addition to having dementia she is also in a wheelchair because of osteoarthritis.” Mr Keith Chard, consultation respondent

- 4.7 One particularly troubling factor about the negative views about dementia that are still widely held is the way such views can lead to people living with dementia (both individuals with dementia and carers) feeling deeply *stigmatised*: as if the disorder were in some way a disgrace or discredit to them. It is striking that, in qualitative research commissioned by the Alzheimer’s Society to explore the experiences of people with dementia across a range of issues, the issue of stigma was said to “permeate” many of the responses to the research, even though only one, final, question in the research questionnaire actually related to the topic.¹⁹¹
- 4.8 The Society’s research, *Dementia: Out of the shadows*, was accompanied by a detailed literature review which highlighted how the disclosure of a diagnosis of dementia may be seen as allocating the individual to a ‘new social group’, associated with devaluation, mistreatment, social exclusion, loss of status and loss of friends.¹⁹² Research carried out by the University of Bradford among families of South Asian and Eastern European origin suggested that some ethnic groups may suffer particularly from fear of stigma: traditional spiritual beliefs about the cause and nature of dementia, and associated concerns about the effect of a person’s dementia on the marriage prospects of younger family members, were found to be not uncommon in South Asian communities; and there was pressure in both groups studied to ‘keep things in the family’ and not expose what was seen as private to public scrutiny.¹⁹³
- 4.9 Personal examples of the experience of stigma cited by the individual participants in *Dementia: Out of the shadows* included unhelpful or dismissive responses from health professionals, with the implication that the person with dementia is beyond any form of help; stereotypical portrayals in the media; and experience of exclusion or rejection in public, with people even crossing the road to avoid a person with dementia. Respondents to our own consultation similarly noted that people with dementia were often avoided, ‘talked down’ to, or the subject of uneasy humour, while carers felt obliged to justify or explain behaviour to strangers that might otherwise seem unusual or rude.¹⁹⁴ Only a very small minority of respondents stated that they had experienced no sense of stigma and had always felt warmly received,¹⁹⁵ or that dementia was seen as so common these days as to have lost its past sense of stigma.¹⁹⁶ Similar concerns about stigma have been reported in many other studies,¹⁹⁷ and it has been argued, in the wider context of mental health services as a whole, that stigma is the main obstacle to the provision of good care.¹⁹⁸
- 4.10 A particularly pernicious aspect of stigma is that it can become internalised: it is clear that many people with dementia *themselves* struggle with a sense of shame and inadequacy and feel ‘lesser

¹⁹¹ Alzheimer’s Society (2008) *Dementia: Out of the shadows* (London: Alzheimer’s Society), p55.

¹⁹² Alzheimer’s Society (2008) *Dementia: Out of the shadows* (London: Alzheimer’s Society), literature review, pp 38–9, citing Husband HJ (1999) The psychological consequences of learning a diagnosis of dementia: three case examples *Aging & Mental Health* 3(2): 179–83 and Katsuno T (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life *Ageing & Society* 25: 197–214.

¹⁹³ Mackenzie J (2006) Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK *Dementia* 5: 233–47.

¹⁹⁴ See, for example, consultation responses from Professor C.G. Swift and Miss Gill Taylor, and the summary of a consultation discussion held by Stockport Dementia Care Training.

¹⁹⁵ Mrs Linda Tolson, responding to the Working Party’s consultation.

¹⁹⁶ Professor Martin Raff, responding to the Working Party’s consultation.

¹⁹⁷ See, for example, the repeated references to stigma in National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), and the outcomes of the project ‘Alzheimer100’ carried out in the North East of England in 2007, available at: www.dott07.com/go/health/alzheimer-100.

¹⁹⁸ Sartorius N (2007) Stigma and mental health *The Lancet* 370: 810–1.

people', as if the damage caused to their brain were discreditable or their own fault.¹⁹⁹ Cary Henderson, an American academic with Alzheimer's disease (see also paragraph 1.16), described his anger at being "belittled", "somehow made jokes of" and being treated as "inferior" and recognised that he himself made such judgments about himself: "I feel that way [no good anymore] and I don't want to feel that way."²⁰⁰ Claire Biernacki, a nurse running day services for people with dementia, commented to us that "the thing people attending the [memory] group most often say in relation to themselves is 'I'm stupid'. So common is this that at the beginning of each session we display a poster that says – 'I may have a poor memory, but I'm not stupid'."²⁰¹

- 4.11 The impact of stigma should not be underestimated. Concern about how others will respond to the news that a person has been diagnosed with dementia may lead many people to keep quiet about their condition, thus depriving them of possible support from friends and relatives (and indeed possibly jeopardising future relationships because of misunderstood changes in behaviour, missed appointments and failure to recognise people). Fear of the stigma of dementia may lead people to delay seeking a diagnosis in the first place,²⁰² while offhand, dismissive responses by health professionals can close the doors to more specialist help.²⁰³ Stigma may make it harder still for people to retain their self-esteem and sense of status within society, as they attempt to come to terms with their changing cognitive abilities and sense of self.²⁰⁴ Moreover, the stigma associated with dementia inevitably has an effect on the status of services and the enthusiasm of professionals and other paid staff to work in them, which in turn may lead to poorer quality care.²⁰⁵
- 4.12 There are many medical conditions, such as serious respiratory or muscular conditions, that, like dementia, can have a major impact on people's lives, but which are not stigmatised in the same way as dementia: the symptoms of such conditions may be feared, but the conditions themselves are not regarded as shameful. The National Audit Office noted in its 2007 report on dementia that a similar attitude to cancer in the 1950s had been transformed by a combination of technological advances, raised awareness and culture change.²⁰⁶ This comparison with cancer suggests a number of inter-related causes of stigma, including ignorance about the condition and a sense of helplessness in the face of a disease for which there is no ready 'cure', leading to fear and denial.
- 4.13 An additional and, in the case of dementia, crucial factor is the fact that the physical damage caused to the brain by the underlying disease has a significant and progressive impact on a person's cognitive abilities and their ability to exert control over their own life, both of which can affect a person's self-esteem and sense of self.²⁰⁷ One person with dementia described her diagnosis as like being "certified as a non-person."²⁰⁸ Moreover, dementia is predominately a disease of old age, a period in life associated with increasing physical decline, vulnerability and dependence. The discrimination and stigma associated with mental illness, with old age and with increased

¹⁹⁹ See, for example, Katsuno T (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life *Ageing and Society* 25: 197–214.

²⁰⁰ Henderson CS (1998) *Partial View – An Alzheimer's journal* (Dallas: Southern Methodist University Press), pp37 and 82.

²⁰¹ Claire Biernacki, responding to the Working Party's consultation.

²⁰² National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p24.

²⁰³ Age Concern (2008) *Out of Sight, Out of Mind: Social exclusion behind closed doors* (London: Age Concern), p35.

²⁰⁴ Katsuno T (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life *Ageing and Society* 25: 197–214.

²⁰⁵ See, for example, consultation responses from June Andrews and Admiral Nurses – 'for dementia'.

²⁰⁶ National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p48. See also Vernooij-Dassen MJ, Moniz-Cook ED, Woods RT et al. (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma *International Journal of Geriatric Psychiatry* 20(4): 377–86, where it is argued that stigma is less prominent in countries where people with dementia have access to memory clinics and innovative services.

²⁰⁷ See, for example, Aminzadeh F, Byszewski A, Molnar F and Eisner M (2007) Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives *Ageing & Mental Health* 11(3): 281–90.

²⁰⁸ Thompson A (2008) Life worth living *Journal of Dementia Care* 16(6): 5.

dependency are well documented.²⁰⁹ Those who are diagnosed with early-onset dementia may experience additional difficulty because of the perception of dementia as “an old person’s disease.”²¹⁰

- 4.14 Finally, many people’s perception of dementia relates primarily to the more advanced stages of cognitive decline, or to the more challenging behavioural symptoms. It may not be widely realised how effectively people in the earlier stages of dementia can function independently with a little appropriate support.²¹¹ Ignorance of the condition leads both to inappropriate concern about how the person will behave (for example, assumptions that people with dementia will always be violent), and also to genuine anxiety about how to respond to, and communicate with, someone with dementia. As one consultation respondent put it: “Society does not deal with difference”²¹² – and as a person’s dementia develops, they may well behave ‘differently.’

Inclusion in ‘everyday’ society

“What is suffered is as much an alienation from the life of society as an alienation from the individual life of the mind.” *Professor David A. Jones, consultation respondent*

“I need the opportunities to join in with everyone else but I also need the chance to meet socially with others like me [with dementia].” *Nancy McAdam, consultation respondent*

“The time for a person to cease to participate in everyday community life is when it becomes distressing and fearful for the individual.” *Older People and Disability Team, Social Care and Learning Department, Bracknell Forest Council, consultation respondent*

- 4.15 Issues of stigma and ‘difference’ lead directly to questions about the inclusion of people with dementia in ordinary life. A diagnosis of dementia may be seen as placing people immediately in an ‘other’ category, where it is assumed that the person will not be able to participate in ordinary activities. As a result, people with early-stage dementia often find that people doubt their diagnosis: the fact that they are functioning perfectly adequately in society is seen as undermining the idea they have dementia at all. Dr Daphne Wallace, a psychiatrist who was still working at the time she received a personal diagnosis of vascular dementia, described to us how she experienced both these aspects of exclusion: when she told her colleagues about her diagnosis, most reacted with denial, while one took the view that Dr Wallace should instantly stop practising medicine without any consideration of whether or not her professional competence was compromised.²¹³
- 4.16 The issue of social isolation is clearly crucial for all those living with dementia – that is both people with dementia themselves and family members or friends closely involved in caring for them, who often find that their caring responsibilities take over their lives. Indeed, social isolation was found to be one of the five ‘key challenges’ facing those living with dementia in the ‘Alzheimer100’ project. This project, which was carried out in 2007 in the North East of England, used interviews, film, diaries and drawing to enable people with dementia and carers to record for themselves the everyday problems they experienced.²¹⁴

²⁰⁹ See, for example, Office of the Deputy Prime Minister (2004) *Mental Health and Social Exclusion: Social exclusion unit report* (London: Office of the Deputy Prime Minister), p24; Age Concern (2007) *Age of Equality? Outlawing age discrimination beyond the workplace* (London: Age Concern), p7.

²¹⁰ Alzheimer’s Association (2008) *Voices of Alzheimer’s Disease* (Chicago: Alzheimer’s Association), p10.

²¹¹ Katsuno T (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life *Ageing & Society* 25: 197–214.

²¹² Annie Foster, responding to the Working Party’s consultation.

²¹³ The Working Party’s fact-finding meeting with people at the front-line of dementia care, 10 July 2008.

²¹⁴ See: www.dott07.com/go/health/alzheimer-100; the other four challenges identified were lack of public awareness/stigma; difficulty in navigating support services; tendency of carers and services to be over-protective of people with dementia; and the long hours worked by carers on their own and without support.

- 4.17 We argued above in Chapter 2 (see paragraph 2.32) that people by their nature are not isolated individuals but rather are embedded in a network of social and family relationships. The ability to create and develop relationships with others is crucial to our well-being, although personal circumstances will clearly vary enormously as to whether those relationships extend very widely or are limited to a small number of close family or friends. There is nothing about dementia that changes this: indeed, the increasing dependency on others which inevitably accompanies dementia emphasises, rather than detracts from, the need for supportive relationships with others. (We will discuss further in Chapter 7 the importance for carers of maintaining their own relationships and social interaction.)
- 4.18 Clearly the symptoms and behaviours associated with dementia do sometimes affect the way a person with dementia engages with others and participates in social events. For example, particular difficult behaviours, such as repeated questioning, shouting or distress, may make it inappropriate for a person to go to a theatre performance.²¹⁵ Moreover, some people with dementia may experience anxiety in crowded or unfamiliar surroundings and may prefer to socialise primarily in small groups or on their home territory where they feel safe and comfortable.
- 4.19 However, such examples should never be used to make the generalisation that people with dementia cannot or should not participate in ordinary activities where they wish to do so. On the contrary, the emphasis in our ethical framework on the value and equality of people with dementia, and the importance of solidarity in responding to the challenges that dementia poses, put the onus on society as a whole to make itself as inclusive as possible towards people with dementia.
- 4.20 Indeed, we note that this is not only a moral obligation, but also in some circumstances a legal one. The Disability Discrimination Act 1995 requires any “provider of services” to make “reasonable adjustments” to ensure that disabled people may use their services, while public bodies such as the NHS and local authorities have a positive duty to take active steps to promote equality for people with disabilities.²¹⁶ However, although the statutory Code of Practice on disabled people’s rights of access to services makes clear that the legislation applies to anyone with a “mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities”,²¹⁷ the Code itself includes just one passing reference to dementia and gives no examples of good practice with regard to “reasonable adjustments” for people with dementia.²¹⁸
- 4.21 Good practice guidance on building ‘dementia-friendly’ environments is becoming available with organisations such as the Dementia Services Development Centre in Stirling,²¹⁹ and the Oxford Centre for Sustainable Development,²²⁰ publishing checklists on both interior and exterior design for people with dementia. Indeed, the development of ‘dementia-friendly’ premises within the NHS is highlighted in the Scottish dementia priority paper,²²¹ and there is growing interest in the

²¹⁵ See: Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q7.

²¹⁶ ss21 and 49A Disability Discrimination Act 1995.

²¹⁷ Disability Rights Commission (2006) *Disability Discrimination Act 1995 Code of Practice: Rights of Access – Services to the public, public authority functions, private clubs and premises* (Norwich: The Stationery Office), p291, available at: www.equalityhumanrights.com/uploaded_files/code_of_practice_rights_of_access.pdf.

²¹⁸ *Ibid*, p92.

²¹⁹ See, for example, Dementia Service Development Centre, University of Stirling (2007) *Best Practice in Design for People with Dementia* (Stirling: DSDC); Health Facilities Scotland and Dementia Service Development Centre, University of Stirling (2007) *Dementia Design Checklist* (Glasgow: Health Facilities Scotland), available at: www.hfs.scot.nhs.uk/publications/dementia-checklist-v1.pdf. See also the Iris Murdoch building at Stirling University which itself is an example of dementia-friendly design. More information available at: www.dementia.stir.ac.uk/about.

²²⁰ Oxford Centre for Sustainable Development and Housing Corporation (2004) *Neighbourhoods for Life* (Oxford: Oxford Brookes University), available at: www.brookes.ac.uk/schools/be/oisd/sue/wise/resources/Neighbourhoods%20for%20Life%20Checklist.pdf.

²²¹ NHS Scotland (2008) *Mental Health in Scotland: Dementia – A national priority summary paper* (Edinburgh: The Scottish Government).

importance of environmental design in specialist dementia care environments.²²² However, practical guidance on what reasonable adjustments ordinary service providers such as shops, leisure services and restaurants could be expected to make for people with dementia is not readily available. Yet relatively minor environmental adjustments, such as clearer signage, strong lighting and non-slip, non-reflective flooring, as well as an increase in staff awareness and understanding of dementia, could do much to make services more accessible to people with dementia, particularly in the relatively early stages.²²³

Box 4.1: Example from practice – making services accessible

“One time I was in Falkirk looking to buy a freezer when a seizure came on. I froze. Eventually someone helped me and asked me what I was looking for: I don’t know but I’ll ken when I see it. They showed me round the shop and when we got to the freezers I said – that’s it.” Ross, *diagnosed with early-onset dementia at age 52, in an extract from a speech to the Alzheimer Disease International Conference, Istanbul, 2005*

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

Box 4.2: Example from practice – Scottish Police College Dementia Awareness Workbook

The Scottish Police College has produced a Dementia Awareness Workbook for all members of staff employed by Scottish Police forces. The workbook, which was developed with Alzheimer Scotland and the Dementia Services Development Centre at Stirling University, aims to provide both police officers and civilian staff with general information about dementia; to offer those who go through the workbook an insight into how dementia affects individuals; and to offer assistance in identifying strategies to deal with operational situations that arise involving people with dementia.

The workbook is not a part of the standard training cycle for police officers and civilian staff, and they may choose to go through the workbook – which takes one to one-and-a-half hours to complete – at a time when it is suitable for their individual role.

Scottish Police College homepage: www.tulliallan.police.uk (Dementia Awareness Workbook not available online).

4.22 Respondents to our public consultation highlighted many practical ways in which people with dementia could be supported to remain active within their existing networks: these included participation in lunch clubs and coffee mornings, involvement in dancing, art and music, other forms of social events, and continued participation in religious activities. It was clear from the responses that many activities can, with a little imagination, be adapted around the needs of a person with dementia: one respondent, for example, described how she and her mother would slip in at the back of their local church for the last half hour of the service and then stay for coffee afterwards, where they were always made welcome. The person with dementia was thus enabled to participate in the life of the church, even if remaining for the full service was no longer possible. Similarly, while a long theatre performance might not be appropriate for a person who forgets where they are, asks questions or has difficulty sitting still, more *ad hoc* art or music performances in open spaces such as theatre or concert hall foyers would not create the same difficulties; nor would more interactive or café-style activities.

4.23 It should also never be assumed that, just because someone has moved into residential care, they are in some way quite separate from the rest of society. An article in the *Journal of Dementia Care*, for example, highlighted how a woman with dementia living in a care home was taken out dancing every month by her husband: as the husband commented, they were simply continuing the habit of a lifetime, and his wife was still able to take enormous pleasure in dance despite retaining very little cognitive ability.²²⁴ While many people living in residential care, with or without cognitive impairments, find it difficult or impossible to continue their past social activities,²²⁵ some

²²² Jones GMM and van der Eerden WJ (2008) Designing care environments for persons with Alzheimer’s disease: visuoperceptual considerations *Reviews in Clinical Gerontology* **18**(1): 13–37; van Hoof J and Kort HSM (2009) Supportive living environments *Dementia* **8**(2): 293–316.

²²³ Blackman T, Mitchell L, Burton E *et al.* (2003) The accessibility of public spaces for people with dementia; a new priority for the ‘open city’ *Disability & Society* **18**(3): 357–71.

²²⁴ Lamont J (2008) Remembering the dance *Journal of Dementia Care* **16**(2): 11.

²²⁵ See, for example, Care Commission and Mental Welfare Commission for Scotland (2009) *Remember, I’m Still Me* (Edinburgh: Mental Welfare Commission for Scotland; Dundee: Care Commission), pp31–5.

care homes nevertheless go out of their way to be part of the local community: for example by hosting local community groups such as mother and toddler groups.²²⁶

4.24 In practice, it is likely to be the *attitudes* of all concerned (people with dementia themselves, carers, those managing services or running clubs or events, and the general public) that determine the extent to which people with dementia may continue to participate in the activities and social life which they enjoyed before they developed dementia. Two responses to our consultation highlight the very different experiences that are possible, depending on attitude:

“I have no evidence that society perceives dementia in a negative way. We took my parents into restaurants and to the theatre for as long as we could and they were always treated with respect and kindness.” Mrs Linda Tolson, consultation respondent

“The presence of a person with dementia can stir up quite a lot of anxiety and hostility among other elderly people ... those running these clubs need to stand up to their members ...” Anonymous consultation respondent

4.25 More supportive attitudes in society, regarding people with dementia first and foremost as *people*, for whose particular needs adaptations may need to be made just as they are for many other groups, would make it much easier for people with dementia to continue to participate in society. Such attitudes would also reduce the pressure on carers to feel obliged to negotiate access to facilities, or justify behaviour which does not meet other social norms. In turn, increased involvement in society may help to normalise dementia in a way that is long overdue.

Box 4.3: Example from practice – faith communities and dementia

Faith in Elderly People (Leeds) was established in 1982 and works to help community groups and churches to understand and improve the care and inclusion of people with dementia. The group encourages and helps people in the Leeds area to visit parishioners who have dementia, with the aim of raising awareness of the value of older people.

More information: www.opforum.webeden.co.uk/#/faithinelderlypeople/4529885856; training materials produced by Gaynor Hammond (gaynor.hammond@northern.org.uk).

The **Caritas Social Action Network (CSAN) Dementia and Spirituality Project** seeks to draw on and build good practice from faith communities in developing awareness of the spiritual and pastoral needs of people with dementia and their carers. It has a particular focus on the Catholic Church and aims to ensure that parishes are communities of understanding which are welcoming to people with dementia and their families. Its work includes the development of training and awareness materials for use with a wide range of people involved in meeting the faith needs of people with dementia, including:

- People with dementia themselves
- Carers
- Staff in residential and nursing care settings
- Religious orders and Catholic voluntary sector organisations
- Clergy and parish communities, hospital chaplains
- Diocesan and deanery advisors
- Eucharistic ministers

More information: www.catholic-ew.org.uk/cfb/catholic_church/the_bishops_work/social_action_caritas/dementia_and_spirituality_project.

Box 4.4: Example from practice – Dementia Adventure holidays

Dementia Adventure is a registered community interest company, whose staff arrange bespoke holidays for people with dementia and their families. They offer three options:

1. Book a holiday guide/companion to accompany and assist you on your normal holiday.
2. Book from a range of pre-planned holiday breaks that have been selected for knowledgeable, user-friendly services and accommodation.
3. Have a custom-made holiday created to suit a specific set of requirements.

All guides have received education about dementia and have been checked with the Criminal Records Bureau (CRB).

More information at: www.dementiaadventure.co.uk.

²²⁶ Ferndale nursing home in Crawley, www.ferndalenursinghome.co.uk/Index.html, personal communication; see also College of Occupational Therapists (2007) *Activity provision – benchmarking good practice in care homes* (London: College of Occupational Therapists) at p13, where the value of community-based activities coming into a care home is emphasised.

4.26 Alongside the importance of inclusion, however, it should also be recognised that most people with dementia clearly value the opportunity to meet, socialise and share experiences with other people in the same position as themselves.²²⁷ The respondents to the Alzheimer's Society research *Dementia: Out of the shadows* strongly emphasised the importance of peer support networks,²²⁸ while one of the proposals emanating from the Alzheimer100 project (see paragraph 4.16) was for social space where people with dementia can talk openly about their experiences and have fun.²²⁹ Age Concern has similarly argued for more befriending projects and support groups, offering "new routes into independence, sociability and well-being" along with "an opportunity to share coping mechanisms."²³⁰ Activities such as 'singing for the brain' seek to meet both needs: providing participation in an activity which is enjoyable and which at the same time enables people facing life with dementia to make new supportive friendships and realise that they are not alone.²³¹

Box 4.5: Example from practice – peer support systems

Alzheimer's Society and Alzheimer Scotland

Both the Alzheimer's Society in England, Wales and Northern Ireland, and Alzheimer Scotland work at a local level to help people with dementia and their carers, and many of their local branches provide support groups for people with dementia and for carers. The Alzheimer's Society website hosts an online forum, 'Talking Point', for "anyone affected by dementia."

Alzheimer Scotland: www.alzscot.org/.

Alzheimer's Society: www.alzheimers.org.uk/site/.

The Clive Project

Based in Oxfordshire, The Clive Project works to help younger people with dementia throughout the county, offering one-to-one support services, family support services, social events held throughout the year, and a monthly café for the people with dementia it supports and their families.

More information: www.thecliveproject.org.uk/index.htm.

DASNI (Dementia Advocacy and Support Network International)

DASNI is a worldwide support organisation run by and for people with dementia. It offers peer support for people with dementia and their families through encouraging local groups, internet forums and counselling group sessions, and providing information about dementia organisations in site users' local areas. It also offers twice-daily internet chats, where those who use the website may discuss their experiences with others in a similar position.

More information: www.dasniinternational.org/.

4.27 We have focused above on the importance of normalising dementia wherever possible, so that people with a diagnosis of dementia can participate, to the extent that they themselves wish, both in activities which reflect their general interests and in 'dementia-specific' services. However, it is important to go one step further and recognise that people with dementia are not only able (and morally entitled) to participate in the activities of wider society: they are also able to make an active *contribution* to those activities, particularly in the earlier stages of their dementia. One respondent to our consultation highlighted the possibility of people with dementia taking an active role in volunteering, with support available as necessary,²³² while another suggested that day centres providing services and support for people with dementia should be run by participants.²³³ One small example of how well this can work in practice can be found in Dorset, where an 86-year-old man with dementia attending a day hospital participated enthusiastically in staff plans to create a 'sensory stairwell', competently undertaking the repainting of the existing wall with only minimal direction and demonstrating clear pride in the outcome.²³⁴ People with early-stage dementia participating in 'town-hall' meetings organised by the American Alzheimer's Association similarly

²²⁷ See, for example, Watkins R, Cheston R, Jones K and Gilliard J (2006) 'Coming out' with Alzheimer's disease: changes in awareness during a psychotherapy group for people with dementia *Aging & Mental Health* **10**(2): 166–76.

²²⁸ Alzheimer's Society (2008) *Dementia: Out of the shadows* (London: Alzheimer's Society), p58.

²²⁹ See: www.dott07.com/go/health/alzheimer-100.

²³⁰ Age Concern (2008) *Out of Sight, Out of Mind: Social exclusion behind closed doors* (London: Age Concern), p36.

²³¹ See: <http://alzheimers.org.uk/singingforthebrain>.

²³² Mrs Debra Catton, responding to the Working Party's consultation.

²³³ Dr Jeremy Harding, responding to the Working Party's consultation.

²³⁴ Benham L (2008) A sensory stairwell *Journal of Dementia Care* **16**(5): pp16–7.

emphasised strongly the importance of self-help and advocacy, with one participant commenting: “We can do all sorts of things until our voices fail us, and then the people who are coming behind us will continue to speak for us.”²³⁵

- 4.28 Guidance issued in 2007 in England by the Department of Health’s ‘Care Services Improvement Partnership’ (CSIP) emphasised the importance of fully involving people with dementia in developing services intended for their use, using a variety of communication methods as appropriate. The guidance also emphasises the distinctions between ‘partnership’ and ‘consultation’: while consultation tends to be a one-off event, through questionnaires or focus groups, a commitment to partnership suggests a much more long-term and equal relationship between service providers and users.²³⁶ This partnership approach embodies the value of solidarity we advocated in Chapter 2 (see paragraph 2.45) and we strongly commend the CSIP Guidance.

Box 4.6: Example from practice – partnerships with people with dementia

PROP (People Relying on People Group) is a support group in Doncaster run by and for younger people with dementia and their carers/partners. The group meets on a weekly basis, with the aim of providing meaningful social activity for younger people with dementia, including art and crafts, gardening, relaxation techniques, and beauty therapy. Members of the group also speak at conferences and training events, act as ‘change agents’ in local services and are involved in staff recruitment.

More information: Department of Health (2005) *User and carer involvement in dementia care*, available at: www.changeagentteam.org.uk/_library/DEMENTIA%20FINAL.doc.

Combating stigma and promoting inclusion: conclusions

- 4.29 We emphasised in Chapter 2 our belief that a person with dementia is to be valued in exactly the same way as a person without dementia. We also set out the importance of solidarity: of recognising each other as ‘fellow-travellers’ in life, with mutual duties of support and assistance. These values underpin a clear moral imperative to tackle the stigma which is still pervasive in dementia and which leads not only to difficulties and delays in accessing services but also to exclusion, to a greater or lesser degree, from mainstream society. We note that the English dementia strategy includes as one of its key aims “improving public and professional awareness and understanding of dementia”, and states the intention of carrying out a national campaign to challenge misperceptions, emphasising that “a person with dementia is no less a person because they have dementia.”²³⁷ The Scottish dementia priority paper and the draft action plan for Wales similarly include commitments on public awareness raising and information.²³⁸ We strongly endorse the emphasis placed on this issue. We also applaud the increasing awareness of the importance of involving people with dementia in developing, and indeed running, services provided by health and social care for their benefit.
- 4.30 Information and awareness campaigns, however, are only one part of the story. For dementia to be truly normalised, it needs to become an accepted, visible part of our society, in the same way that physical disability is increasingly recognised as part of the norm. People with dementia need to feel comfortable going to a club or a class or out to lunch, participating in the life of a church, or taking part in voluntary work, just as they did earlier in their lives. We highlighted in paragraph 4.20 that those providing “services” to the public (including restaurants, shops, theatres, leisure centres, places of worship and private clubs, as well as public services and public utilities) have

²³⁵ Alzheimer’s Association (2008) *Voices of Alzheimer’s Disease* (Chicago: Alzheimer’s Association), p27.

²³⁶ Care Services Improvement Partnership (2007) *Strengthening the Involvement of People with Dementia: A resource for implementation* (London: Department of Health), pp20–1, available at: www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf.

²³⁷ Department of Health (2009) *Living Well with Dementia: A national dementia strategy* (London: Department of Health), pp24–8.

²³⁸ 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), pp14–5 and 34.

a legal duty under the Disability Discrimination Act 1995 to make “reasonable adjustments” to enable people with dementia to access those services. However, they will often not realise this, and even if they do, they are unlikely to have sufficient knowledge of dementia to make appropriate adjustments.

- 4.31 The Equality and Human Rights Commission has a remit to enforce equality law, including the Disability Discrimination Act 1995; to promote good practice with respect to equality and human rights in the public, private and voluntary sector; and to undertake high-profile media campaigns to highlight particular equality issues.²³⁹ It is therefore well-placed to provide the practical guidance required to ensure that people with dementia are able to access services in the same way as anyone else, with or without disabilities.

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

The role of society in providing care and support

- 4.32 We have argued above that we have an ethical obligation to become more inclusive of people with dementia, enabling them to participate in everyday life as much as possible. What additional duties, if any, does the state, and society as a whole, have towards people with dementia and their families?
- 4.33 At present, the needs of people with dementia are met by a combination of state support, family support and, depending where people live, support from the voluntary sector, such as local Alzheimer’s societies, Alzheimer Scotland groups or Age Concern groups. Sometimes, particularly in the earlier stages of dementia, the only source of help will be the family and any local voluntary sector support that happens to be available. Where the person with dementia has their own financial resources, they will be expected to contribute to the cost of most state services, with only NHS services (and, in Scotland only, personal care services) being provided free of charge. ‘Social care’ services include residential care, where individuals will be expected to pay as much as they can towards the cost of their care themselves, unless their nursing needs are sufficiently acute for them to qualify for ‘NHS continuing health care’.²⁴⁰ In many circumstances this will involve selling their home, a requirement which generated many angry comments in our consultation responses.²⁴¹
- 4.34 The nature of many of the support services required by people with dementia, such as practical help in the home, assistance with personal care, help with finances, and advocacy, is such that these are classed as ‘social’ care. This classification has two implications: first, unlike NHS services, they will usually be charged for (with the charge usually being dependent on the person’s financial position); and, secondly, the pressure on social services is such that support will often be made available only to those with very high needs. The recent National Audit Office report on dementia services in England highlighted the perversity of a system that is often unable to provide early-stage support, even though such support may contribute significantly to maintaining a person’s independence in

²³⁹ See: www.equalityhumanrights.com/our-job/what-we-do/.

²⁴⁰ In England, Scotland and Wales (but not in Northern Ireland at the time of writing) a person may be assessed as having such complex nursing needs that the full cost of their care, including care in a private nursing home, will be met by the NHS.

²⁴¹ Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q24.

their own home for much longer.²⁴² Audit Scotland and the ‘Sutherland Review’ of free personal and nursing care in Scotland have similarly highlighted difficulties around financial shortfalls for personal and social care and associated geographical variations in eligibility criteria.²⁴³

4.35 In England, there is an increasing acceptance both that the current system is not delivering adequate services, and that pressures on the system are due to increase considerably as the population ages. In 2006, the independent health policy organisation the King’s Fund published its ‘Wanless Report’, which recommended moving away from the current system of means testing for personal and social care to a ‘partnership model.’²⁴⁴ In such a model, the state would guarantee a minimum level of care, and would then match personal contributions pound for pound up to a ‘benchmark’ level. Those on low incomes would receive help through the benefits system to meet their personal contributions. Wanless’s proposals (which called for improvements in the kind and quality of care provided, as well as in the funding mechanism) would require funding increases in the order of 50 per cent, from £6.2 billion to £9.7 billion in 2004–5 prices.

4.36 In July 2009, the Government published a consultative Green Paper setting out its own vision of a new care and support system in England that would be “fair, simple and affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs.”²⁴⁵ The Green Paper proposes a National Care Service which would guarantee everyone in England:

- Prevention services – the right support to stay independent and well for as long as possible and to delay care needs getting worse.
- National assessment – care needs to be assessed and paid for in the same way across the country.
- Joined-up services – all services to work together smoothly.
- Information and advice – a care system that is easy to understand and navigate.
- Personalised care and support – services based on personal circumstances and need.
- Fair funding – money to be spent wisely and everyone to get some help meeting the high cost of care needs.²⁴⁶

The Green Paper also proposes three options for funding the National Care Service:

- ‘Partnership’, where the Government would pay between a quarter and a third of the cost of care, with individuals funding the remainder;
- ‘Insurance’, a voluntary scheme where the Government would pay the same proportion as under the partnership approach, and would also make it easier for people to take out insurance to cover care costs; and
- ‘Comprehensive’, a compulsory scheme where everyone who can afford it would pay into a state insurance scheme at a cost of around £17,000 to £20,000 which would provide free basic care to those who need it.²⁴⁷

4.37 Alongside this commitment to creating a new approach to adult social care services, the Department of Health in England has also been piloting the idea of ‘individual budgets’, with the aim of giving

²⁴² National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), paragraphs 3.13 and 4.8.

²⁴³ Audit Scotland (2008) *A Review of Free Personal and Nursing Care* (Edinburgh: Audit Scotland), p4; Scottish Government (2008) *Independent Review of Free Personal and Nursing Care in Scotland: A report by Lord Sutherland* (Edinburgh: The Scottish Government), pp4–9.

²⁴⁴ King’s Fund (2006) *Securing Good Care for Older People: Taking a long-term view* (London: King’s Fund).

²⁴⁵ HM Government (2009) *Shaping the Future of Care Together* (London: HM Government).

²⁴⁶ See: HM Government press release (2009) *Government launches the Big Care Debate* 14 July, available at: <http://careandsupport.direct.gov.uk/news/2009/07/government-launches-the-big-care-debate/>.

²⁴⁷ HM Government (2009) *Shaping the Future of Care Together* (London: HM Government), p95.

individuals more choice and control over their care. The system of 'direct payments' for social care, where the person needing care has the option of receiving the value of services in the form of a cash payment and then making their own care arrangements, has been in existence for some time throughout the United Kingdom. The idea of 'individual' budgets is to create a more flexible system, where the person knows from the start how much money is available (either from social services alone, or from more integrated funding sources), and then has maximum choice over how it is spent.²⁴⁸ Similar projects are being developed in Scotland (see Box 3.10) while Northern Ireland is committed to introducing free personal care, as in Scotland.²⁴⁹ The Welsh Assembly Government has promised to support the expansion of 'direct payments' for care services, while keeping under review the possibility of other forms of individual budgets in the light of the English pilot schemes.²⁵⁰

4.38 We do not wish to make specific recommendations that may have significant economic implications, nor recommendations about the precise balance to be maintained between individual, family and state financial contributions to the cost of care. This is because we are not in a position to consider the 'opportunity costs' of any such recommendation. However, we welcome the fact that such a wide-ranging debate is currently taking place and we would like to make the following observations in connection with the particular needs of people with dementia, based on our ethical framework set out in Chapter 2.

4.39 People with dementia experience a number of disadvantages in the current system, especially in the way services are subdivided into 'social' and 'health' services, and indeed they may sometimes get 'lost' between the two systems. Their needs are largely classed as 'social', despite the fact that the direct cause of their highly complex symptoms is progressive damage to the brain, and all the evidence suggests that much more skilled care than is currently generally on offer would significantly enhance the quality of people's lives and promote independent living.²⁵¹ Under the current system, this means that support services may only be made available when a crisis has already been reached because of the pressure on social services departments to prioritise those in greatest need.²⁵² Moreover, the level of 'hidden' dementia, particularly among those living in care homes, means that even where people are in touch with social care systems, their particular needs arising out of their dementia may not be recognised.²⁵³

4.40 We have already argued in Chapter 2 that dementia is a medical disorder and that the needs arising out of the disorder should therefore be met in just the same way as those arising out of, for example, cancer. We have also argued that people with dementia should be valued in just the same way as people without dementia. It is not acceptable to make people with cancer wait until their support needs have reached a crisis before providing that support and nor should it be regarded as acceptable for people with dementia to wait in this way. Rehabilitative and supportive health services such as physiotherapy, occupational therapy, speech therapy and psychological therapies must be as readily available to people with dementia, as they are to people diagnosed with other serious medical disorders, on the basis of clinical need and efficacy. There should also be serious consideration given to the extent to which some of the traditionally 'social' services provided for

²⁴⁸ Department of Health (2005) *Independence, Well-being and Choice* (Norwich: The Stationery Office); Social Policy Research Unit, University of York and Personal Social Services Research Unit, University of Kent (2009) *The Individual Budgets Pilot Projects: Impact and outcomes for carers* (York: Social Policy Research Unit, University of York; Canterbury: Personal Social Services Research Unit, University of Kent).

²⁴⁹ Department of Health, Social Services and Public Safety, NI Executive press release (2009) *Minister still committed to introducing free personal care* 18 May, available at: www.northernireland.gov.uk/news/news-dhssps-18052009-minister-still-committed.

²⁵⁰ Welsh Assembly Government (2007) *A Strategy for Social Services in Wales Over the Next Decade: Fulfilled lives, supportive communities* (Cardiff: Welsh Assembly Government), p23.

²⁵¹ All-Party Parliamentary Group on Dementia (2009) *Prepared to Care* (London: Alzheimer's Society), paragraph 28.

²⁵² National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p43.

²⁵³ See, for example, Alzheimer's Society (2007) *Home from Home* (London: Alzheimer's Society), p7.

people with dementia, especially those relating to personal care and those being provided to people experiencing significant behavioural and psychological symptoms, need skilled nursing and psychological input.

- 4.41 **The essential ethical point to be made is that the access of people with dementia to the services they need should not be determined by classifications of care. In allocating resources, and in determining standards of care, it should make no difference whether the intervention is classified as ‘health’ or ‘social’.** If the intervention addresses a problem that arises as a result of the disorder then the level of priority given to providing that intervention should be based on the needs of the person and the benefits and the costs of the intervention and not on which service provides it. Any future proposals relating to adult social care services must take this point fully into account, despite the current difficult economic climate.
- 4.42 The discussion above relates mainly to the duties of the ‘state’, in terms of the welfare support and services made available through statutory bodies. Individuals obviously contribute to that support through taxation. However, we believe that ‘society’ has a broader role than simply contributing financially to state activity. In Chapter 2, we put forward the value of ‘solidarity’ to underpin our approach to dementia, arguing that we have duties to support and help each other and in particular those who cannot readily support themselves.
- 4.43 We have highlighted above (see paragraphs 4.15–4.25) that one way in which this solidarity can be expressed is through practical steps to promote the social inclusion of people with dementia. A further way in which solidarity can be made real in practice is through the more widespread use of voluntary activity. Organisations such as local Alzheimer’s societies, Age Concern groups and Alzheimer Cafés depend on volunteers to run a range of services, including advocacy, befriending and sitting services, and practical domestic help such as shopping, help in the house and gardening. While many individuals may underestimate the potential value of what they can offer or may be unsure how to put themselves forward, specialist national organisations such as Timebank²⁵⁴ do exist to match those interested in volunteering with organisations which can make use of their particular interests and skills, and emphasise that even just one hour a week can be a valuable contribution.
- 4.44 It is well recognised that there are a number of factors that may deter, obstruct or delay people who might otherwise volunteer. These include:
- delays with carrying out Criminal Records Bureau checks;
 - excessive and inappropriate bureaucracy;
 - expenses incurred by volunteers;
 - concern by potential volunteers that they would lose entitlement to benefits;
 - stereotypes about the age and sex of volunteers;
 - risk aversion on the part of organisations that could benefit from volunteers;
 - organisations’ insurance policies not covering volunteers; and
 - antipathy towards the use of volunteers in profit-making companies.²⁵⁵

The Commission on the Future of Volunteering has recommended that the Government should set up a working party with stakeholders in order to remove any unnecessary or disproportionate obstacles to volunteering,²⁵⁶ and we warmly endorse this proposal.

²⁵⁴ See: www.timebank.org.uk/about/connecting_volunteers.php.

²⁵⁵ Adapted from: The Commission on the Future of Volunteering (2008) *Report of the Commission on the Future of Volunteering and Manifesto for Change* (London: The Commission on the Future of Volunteering); The Cabinet Office (2008) *Volunteering in the Public Services: Health & social care – Baroness Neuberger’s review as the Government’s Volunteering Champion* (London: The Cabinet Office).

²⁵⁶ The Commission on the Future of Volunteering (2008) *Report of the Commission on the Future of Volunteering and Manifesto for Change* (London: The Commission on the Future of Volunteering), recommendation 2.2. The Commission is chaired by Baroness Neuberger, the Government’s volunteering champion.

Box 4.7: Example from practice – the role of volunteers

The Evergreen Care Trust

Based in Stamford, Lincolnshire, the Evergreen Care Trust gives volunteers the opportunity to provide practical assistance to older people – including those with dementia – in the local community.

The Trust offers volunteers the opportunity to befriend older people in the community, provide hospital-to-home support, become a member of the Trust's Clean Team where an older person's living accommodation needs some attention, or help to provide meals for the older person.

More information: <http://evergreencare.org.uk/>.

Leeds Neighbourhood Network Schemes

Schemes in the Leeds area, run by and for older people, provide health information and advice to older people in order for them to remain independent and healthy. They provide practical assistance, in the form of support groups, transport to appointments and prescription collection.

More information: www.leeds.gov.uk/page.aspx?pageidentifier=3ead6668-e3f7-4c61-ad4c-d433220f5f30.

Finding out about volunteering opportunities

The 'Direct Gov' website provides helpful information about volunteering, along with a link to a volunteering database searchable by postcode and type of activity.

More information: www.direct.gov.uk/en/Dio1/DoltOnline/DoltOnlineByCategory/DG_069041.

Use of volunteers in Dutch dementia care

At the **Osira Group** of residential and nursing care homes in south west Amsterdam, all of which have specialist dementia care facilities, there are more than 1,000 registered volunteers. An ex-nurse manager is the full-time co-ordinator for this group. There is a 'volunteers' agreement' and compensation for travel costs. Volunteers agree to a dress and behaviour code. They are given the education and support required to do their particular activities and are insured for accidents and legal liabilities during their activities. They support residents in a wide range of activities from art, craft and cultural activities, dancing, cooking, swimming and day trips, to doing their nails, playing games, chatting and reading to them.

More information: www.osiragroep.nl/vrijwilligers_401.html [in Dutch].

Training materials for 'befriending' volunteers

Befriending Network Scotland and Alzheimer Scotland are developing a volunteers' dementia training programme, due to be published in summer 2009. The Dementia Training Toolkit will include materials for befriending co-ordinators to train their volunteers in all aspects of befriending clients with dementia and will contain sections on: understanding dementia and befriending; building relationships; maintaining relationships (for example stimulating memory, life story work, motivating clients); dealing with challenges; and recording and reacting to change.

More information: www.befriending.co.uk/news_more.php?id=7.