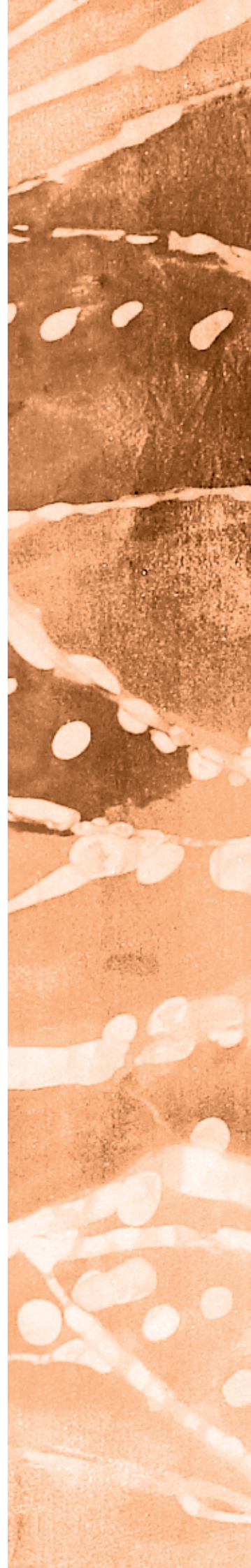


Chapter 7

The needs of carers



Chapter 7 – The needs of carers

“Although there is no standard definition of family caregiving, it is understood to involve providing extraordinary care, often outside the bounds of what is usual in family relationships.”³⁷⁷

“... the informal family caregiver is a tribute to the human spirit. He or she is an altruist in the full sense of caring for another at considerable inconvenience to self.”³⁷⁸

Introduction: the role of carers

- 7.1 A ‘carer’ is defined in the UK Government’s Carer’s Strategy as someone who “spends a significant proportion of their life providing unpaid support to family or ... friends.”³⁷⁹ An analysis of carers in England derived from the 2001 census found that the majority of carers are of working age, although one in six are over 65, and that half live with the person for whom they provide care.³⁸⁰
- 7.2 For many people with dementia, the support they receive from carers will be their main source of assistance. The National Audit Office reports that there are some 476,000 unpaid carers in England supporting people with dementia,³⁸¹ and the 2007 *Dementia UK* report estimated that on average people with dementia receive 24 hours of care per week from carers, with that figure rising to 60 hours for those needing the most care.³⁸² A survey by Alzheimer Europe similarly reported that half of carers of people with late-stage dementia spend more than ten hours each day caring,³⁸³ while over 80 per cent of the total care received by people with dementia in one Swedish study was provided by informal, rather than paid, carers.³⁸⁴
- 7.3 The support provided by a carer for a person with dementia will vary enormously depending on the nature and progress of the person’s dementia, on the capabilities of the carer, and on what other assistance, if any, is available. It may include helping the person with some or all activities of daily living, from intimate personal care to housework; supporting the person in meaningful occupation; providing constant reassurance where the person fears being alone; helping with, or managing, financial and legal matters; and many other forms of support. Providing this level of constant support takes a great deal of time, hard work and compassion, and may often be emotionally and physically exhausting. A study of carers of people with dementia, stroke and Parkinson’s disease found that the most frequently reported problems associated with caring were the disorganisation of household routines, difficulties with going away for holidays, restrictions on social life, and disturbances of sleep.³⁸⁵
- 7.4 In Chapter 2 we set out our ethical framework, highlighting our belief that a good quality of life is possible with dementia, but that in order to achieve this, significant support will be required

³⁷⁷ Yap LKP, Seow CCD, Henderson LM and Goh YN (2005) Family caregivers and caregiving in dementia *Reviews in Clinical Gerontology* 15: 263–71.

³⁷⁸ Post S (2000) *Ethical Issues from Diagnosis to Dying: The moral challenge of Alzheimer’s disease*, 2nd Edition (Baltimore: Johns Hopkins University Press), p25.

³⁷⁹ HM Government (2008) *Carers at the Heart of 21st Century Families and Communities: “A caring system on your side. A life of your own”* (London: Department of Health), p19.

³⁸⁰ Audit Commission (2004) *Support for Carers of Older People* (London: Audit Commission), p2.

³⁸¹ National Audit Office (2007) *Improving Services and Support for People with Dementia* (Norwich: The Stationery Office), p9.

³⁸² Knapp M and Prince M (King’s College London and London School of Economics) (2007) *Dementia UK* (London: Alzheimer’s Society), p66.

³⁸³ Alzheimer Europe (2006) *Who Cares? The state of dementia care in Europe* (Luxembourg: Alzheimer Europe).

³⁸⁴ Wimo A, von Strauss E, Nordberg G, Sassi F and Johansson L (2002) Time spent on informal and formal care giving for persons with dementia in Sweden *Health Policy* 61: 255–68.

³⁸⁵ Thommessen B, Aarsland D, Braekhus A et al. (2002) The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson’s disease *International Journal of Geriatric Psychiatry* 17(1): 78–84.

to promote both the person's autonomy and their well-being. At the same time, we emphasised that the autonomy and well-being of carers were also morally important. Unlike care workers and professionals, a carer's responsibilities will often continue day and night and this may have very significant practical consequences: for example, additional stress and sheer exhaustion caused by broken nights may seriously affect both the health of the carer and their ability to provide care in the way that they would ideally like to do.³⁸⁶ More fundamentally, however, it is crucial to recognise that the life of the person with dementia and their carer will often be very closely entwined, particularly where informal care is being provided by a partner, or by a relative living in the same house.

- 7.5 In such circumstances, the interests of the person being cared for and the person providing the care will often be inseparable, and this may have significant implications for how the various needs and interests at stake are balanced and compromises sought. Moreover, in providing care to a partner, close family member or friend, carers have to contend with their own complex emotions resulting, for example, from the changes in their relationship with the person with dementia, or from the loss of cherished future plans.³⁸⁷
- 7.6 While the pressure placed on carers by their caring role should not be underestimated, it is important also to highlight that for many carers the experience of caring for their relative or friend has many positive aspects.³⁸⁸ Caring is often a key part of family relationships, and may offer carers an opportunity to express feelings of love, and also to act altruistically. Descriptions of caring recently published in the health care press by two individual carers, each of whom provided care to their wives with dementia, highlight some of these positive aspects:

"Caring does not constitute a cure, but it certainly can reveal one's inner strengths. It has its own rewards."³⁸⁹

"We [husband and wife] have been marked by a special kind of pain. But we have also experienced a deepening sense of responsibility, gratitude for all that we had lived through together, love, solidarity, and a shared sensibility that we have resisted what is beyond our control and are, individually and collectively, more for it."³⁹⁰

As the second quotation illustrates, 'caring' should not automatically be seen as a one-way process: for many people with dementia and their carers, the experience of being cared for and providing care will be closely tied up with the nature of their relationship. Indeed, as we note in Chapter 2 (see paragraph 2.45), the person with dementia should not be portrayed simply as a passive recipient of care, but rather as someone who has the potential to continue participating in family life, albeit in different ways from before.

Attitudes and beliefs about caring

"People find themselves looking after a confused person at home for many different reasons – out of love, from a sense of duty, perhaps because they feel they have no choice. Some find assuming responsibility relatively easy. Others come increasingly to resent it."³⁹¹

³⁸⁶ Dauvilliers Y (2007) Insomnia in patients with neurodegenerative conditions *Sleep Medicine* **8(4)**: S27–S34.

³⁸⁷ See, for example, Schneider J, Murray J, Banerjee S and Mann A (1999) EURO CARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I – Factors associated with carer burden *International Journal of Geriatric Psychiatry* **14(8)**: 651–61.

³⁸⁸ Netto NR, Goh JYN and Yap PLK (2009) Growing and gaining through caring for a loved one with dementia *Dementia* **8(2)**: 245–61.

³⁸⁹ Lamont J (2008) Remembering the dance *Journal of Dementia Care* **16(2)**: 11.

³⁹⁰ Kleinman A (2009) Caregiving: the odyssey of becoming more human *The Lancet* **373**: 292–3.

³⁹¹ Department of Health (2007) *Who Cares? Information and support for the carers of people with dementia* (London: Department of Health), p15.

“The reaction of the family and friends to the diagnosis can be crucial to the carer and patient. If it is good and positive, and accepted as an illness with no known cure as yet but one that will have its good and bad times, life for the carer and the patient can be very rewarding.” Jean Burnard, consultation respondent

- 7.7 Most carers do not plan to be a carer, and nor do they receive special education about dementia or the effects it may have on their own lives. Indeed, a person will often not make a specific conscious decision to take on a caring role; rather it will evolve out of a relationship as a result of shifting levels of dependency.³⁹² Some people dislike being classified as ‘carers’ in the very early stages of dementia, seeing themselves as acting as caring partners, relatives or friends, rather than taking on a new role with a new name.³⁹³
- 7.8 Like the experience of dementia itself, the personal experience of being a carer, and the extent to which the positive aspects of providing care are outweighed by the physical and emotional burdens, is likely to be affected by a wide range of factors. These potentially include the personal characteristics of all involved, the nature of their relationships, the needs of the person with dementia, and the level of support received from others. In particular, the carer’s beliefs about caring are likely to affect how the role is experienced.
- 7.9 One UK-based study in 2008 of three different ethnic groups classified attitudes to caring as ‘traditional’, where caring within the family was seen as natural, expected and virtuous, and ‘non-traditional’, where the carer perceived their own life as being ‘on hold’ while providing care and did not necessarily expect to derive reward or pleasure from caring. It found that while all carers in the study experienced health difficulties (particularly linked with exhaustion) as a result of their caring role, a more ‘traditional’ attitude helped carers find rewards in their relationship with the person for whom they were caring, and to feel that their lives, although changed, were ongoing. Although ‘traditional’ views were more common among carers of south Asian or Caribbean origin than among white British carers, ‘traditional’ and ‘non-traditional’ attitudes were identified among all three ethnic groups studied, thus emphasising the need for professionals to consider the specific needs and experiences of individual carers, without making prior assumptions about their likely attitude to caring.³⁹⁴
- 7.10 Where one person within a family or social circle takes on primary responsibility for providing care, the attitudes and assumptions about care within the wider family or network may also have a significant impact on the main carer. The extent to which the main carer feels supported may depend to a significant degree on how the rest of the family unit reacts both to the person with dementia and their carer. On the one hand, relatives outside the relationship between the main carer and the person with dementia may decide what the person with dementia and their main carer need, without first consulting them.³⁹⁵ On the other hand, family members who have only limited contact with the person with dementia may underestimate how much support the person needs in day-to-day living, and hence fail to understand the degree of pressure under which the main carer is living.³⁹⁶ Again, distinctions between ‘traditional’ and ‘non-traditional’ attitudes to

³⁹² Gillies B (2000) Acting up: role ambiguity and the legal recognition of carers *Ageing and Society* 20: 429–44.

³⁹³ Goldstein M, Abma T, Oeseburg B *et al.* (2007) What is it to be a daughter? Identities under pressure in dementia care *Bioethics* 21(1): 1–12.

³⁹⁴ Lawrence V, Murray J, Samsi K and Banerjee S (2008) Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK *British Journal of Psychiatry* 193: 240–6.

³⁹⁵ Zarit SH and Zarit JM (2008) Flexibility and change: the fundamentals for families coping with dementia, in *Excellence in Dementia Care: Research into practice*, Downs M and Bowers B (Editors) (Maidenhead, UK: Open University Press), p93.

³⁹⁶ See, for example, NHS Health Scotland (2008) *Coping with Dementia: A practical handbook for carers* (Edinburgh and Glasgow: Health Scotland), p19.

the role of the family in providing care may play an important role, with evidence to suggest that families with more 'traditional' attitudes regard asking for professional help as a sign of failure.³⁹⁷

- 7.11 Carers may also find that there is no plateau to their caring role because of the degenerative nature of dementia. Continuous adjustments and adaptations may have to be made just at the point when the carer is starting to feel more competent and confident with what has just been achieved. Care requirements increase even though the carer's own health and resources may be diminishing, especially in the case of spouse or partner carers. Particular difficulties may arise when the person with dementia denies that there is anything wrong and refuses to accept any sort of additional help from paid care workers.
- 7.12 Many carers continue to see themselves as carers even when the person with dementia has moved into a care home, right up until the person with dementia dies. Writing about her experiences of caring for her mother with Alzheimer's disease, one carer notes that her "whole identity is shot through with being a carer. How can I stop thinking of myself as a carer just like that?"³⁹⁸ However, some stop considering themselves as 'real' carers once the person with dementia is being cared for by others and then struggle to redefine their relationship with their loved one.³⁹⁹

Our approach

- 7.13 In Chapter 2 of this Report, we put forward the argument that the idea of solidarity is a key component in an ethical framework for the care and support of people with dementia. The concept of solidarity suggests that our response to the challenges presented by the increasingly common disorders leading to dementia should be one of 'fellow-travellers' where we seek to support and help one another. Families and friends demonstrate practical solidarity in the care and support they provide to people with dementia, whether this is given primarily out of love, compassion, duty, a desire to reciprocate past support, or a combination of all of these. We suggest that solidarity similarly urges us (as individuals, families, communities and through the state) to support carers in their own exercise of solidarity with those for whom they care.
- 7.14 Our ethical framework in Chapter 2 further emphasises the importance of giving close attention to the autonomy and well-being of carers. This is partly because, in doing so, the autonomy and well-being of people with dementia are likely to be enhanced: a carer who feels properly supported and appreciated by others is likely in turn to be able to provide more supportive care and hence a better quality of life for people with dementia.⁴⁰⁰ We also argue that autonomy should be seen in 'relational' terms: that is, that a person's sense of self and self-expression should be seen as being firmly grounded in their social and family networks. In addition, most people would wish that their carer's interests should be given considerable weight: their interests include their carer's interests. When autonomy is understood in these terms, then in order to support a person's autonomous wishes and values it will be necessary to support the whole family and social structure.
- 7.15 However, we also strongly advocate paying attention to the autonomy and well-being of carers because carers are people in their own right, whose own interests are important quite outside any associated benefit to the person with dementia. The very fact that carers are likely to neglect or

³⁹⁷ Lawrence V, Murray J, Samsi K and Banerjee S (2008) Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK *British Journal of Psychiatry* **193**: 240–6.

³⁹⁸ Healthy Living Blog (2008) Why caring makes you truly human, available at: www.saga.co.uk/health/healthyliving/blog/carer-diary/july-3-2008-why-caring-makes-you-truly-human.asp.

³⁹⁹ Goldstein M, Abma T, Oeseburg B *et al.* (2007) What is it to be a daughter? Identities under pressure in dementia care *Bioethics* **21**(1): 1–12.

⁴⁰⁰ Brodaty H, Green A and Koschera A (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia *Journal of the American Geriatric Society* **51**: 657–64.

even deny their own interests in order to promote the interests of the person for whom they care suggests that society, in the form of the professionals it employs, should have a concern for the interests of the carers, not only for the sake of the person with dementia but also for the sake of the carers themselves.

- 7.16 Alongside these ethical reasons for recognising the need to help and support carers, a purely pragmatic financial point should also be noted: if carers did not take on their roles to the extent they currently do, the financial impact on the state would be enormous, as the monetary value of the care provided by family and friends to people with dementia has been estimated at £5.4 billion in England alone.⁴⁰¹ Indeed, the point has been made that the only affordable way in the long term to provide care for people with dementia in both the developed and developing world is for support to be delivered through carers.⁴⁰²
- 7.17 We discussed in Chapter 4 how as individuals we could support people with dementia and their carers, both in our attitudes to and acceptance of dementia, and in some cases through practical voluntary help to those we know in our community who need support. We discuss below the role that the state and the voluntary sector, as providers and funders of health and social care services, can play in supporting carers. We consider help and support for carers first in terms of their role as carer and secondly in terms of their own personal needs as individuals.

Help and support for carers in their caring capacity

Joint support for the person with dementia and their carer

“Caring for a relative with dementia, of course, presents family carers with specific and complex problems. These can be exacerbated if their experience is framed within a medical model of care provision, a model which redefines the largely social consequences and which offers little in the way of helpful information.”⁴⁰³

- 7.18 As we suggested earlier (see paragraphs 3.22 and 7.5), a diagnosis of possible dementia has implications that extend well beyond the individual receiving the diagnosis. Close family and friends, and especially the partner of the person with dementia, have to adjust to the ramifications for their own lives and come to terms with a shared future which may be very different from what they had all envisaged. We have already emphasised the need for appropriate information and follow-up for the person with dementia at the point of diagnosis (see paragraphs 3.25–3.29) and we note here the importance of ensuring that the information needs of carers, too, are met.
- 7.19 **An important implication both of our emphasis on solidarity and of our ‘relational’ approach to autonomy (see paragraph 7.14) is to emphasise that professional support should have a wide focus that includes helping family and friends to support the person with dementia, rather than being limited to an exclusive and direct focus on the person with dementia.** In much of medical care where people’s ability to care for themselves and their mental capacity are not greatly affected, it is appropriate for health and social services to be focused almost exclusively on the patient or client. These models of service delivery may not be appropriate in dementia care, at least at some stages, where the major part of the care is delivered by the family or other carers. We highlight in Box 7.1 below the example of Admiral Nurses, whose approach is very much predicated on providing care to people with dementia *through* their existing family and other support networks.

⁴⁰¹ National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p9.

⁴⁰² See, for example, Ferri PF, Prince M, Brayne C *et al.* (2005) Global prevalence of dementia: a Delphi consensus study *The Lancet* **366**: 2112–7; Zaida A (2008) *Features and Challenges of Population Ageing: The European perspective* Policy Brief **March (1)** (Vienna: European Centre for Social Welfare Policy and Research).

⁴⁰³ Gillies B (2000) Acting up: role ambiguity and the legal recognition of carers *Ageing and Society* **20**: 429–44.

Box 7.1: Example from practice – Admiral Nurses

Admiral Nurses are specialist mental health nurses who have experience in working with dementia. They support and work in partnership with people with dementia, their families, and their social networks. Admiral Nurses focus on working with carers, providing them with practical advice, emotional support and information. They visit carers and people with dementia in their own homes for as long as they are needed, working with carers throughout the duration of the person with dementia's illness. Admiral Nurses also deliver education and training in dementia care, and provide consultancy services to professionals working with people with dementia.

Currently, Admiral Nurses operate in certain areas of England, including London, Kent, North East Lincolnshire, the West Midlands and the North West, and in North Wales.

More information: www.fordementia.org.uk/admiral.htm.

Care partnerships

"In dementia care, there is much greater openness with carers (rightly or wrongly) than in other mental health contexts, and the need for partnership with family carers is widely recognised." Professor Bob Woods, consultation respondent

"Carers' skills must be recognised as such, working in partnership with a professional ... so that the relationship of trust and honesty is built up." Dementia Services Development Centre (South East), Canterbury Christ Church University (Mrs Penny Hibberd, Admiral Nurse/Senior Lecturer), consultation respondent

- 7.20 Carers will often know the person with dementia better than anyone else, and hence are likely to be well placed to advise on their particular support needs. However, they do not necessarily know about the nature or progression of dementia, nor what care interventions are possible. Support is therefore needed from professionals who do possess such knowledge. Conversely, health and social care professionals will be familiar with care planning, care provision and caregiving, but unfamiliar, at least initially, with the personal history, preferences and values of the person with dementia. As we note in Chapter 3 (see paragraph 3.12), it is therefore crucial that professionals and carers work together in genuine partnership, in order to ensure that people with dementia benefit from their joint expertise and joint knowledge.
- 7.21 Such a 'care partnership' should be founded on a basis of mutual respect for the different forms of knowledge of the different parties, and on the premise that all concerned are seeking to help the person live as well with their dementia as possible. We note in Chapter 3 (see paragraphs 3.30 and 3.31) the importance of ensuring that where formal services are available, they should be offered on a flexible basis, matched to the actual needs and wishes of those receiving them and to the support that carers are able and willing to offer.
- 7.22 As dementia progresses, the needs of both the person with dementia and their carer are likely to change significantly, and at some point it may become appropriate for the person to move into residential care, or for more formal support to be provided in the person's own home. It is imperative in such circumstances that the carer's continuing role is acknowledged, and that carers should be given opportunities to sustain whatever input they are able to contribute to the care for as long as they wish. When the level of formal support increases in this way, there should never be an 'all or nothing' assumption about the carer's desire to be involved or ability to cope. Some carers will wish to continue providing particular forms of care and support, such as washing their loved one's clothes, or taking in favourite food, even where the person with dementia is being cared for in a residential environment. Others may be happy to relinquish such tasks to others, but are still a rich source of information for those now providing day-to-day care for the person – for example through providing 'life-story books' to accompany the person into residential care.

The need to be trusted

“To be cared for by others requires trust in the carer. It requires recognition of the carer as caring and of the importance of human community.” *CARE, consultation respondent*

“I think with something like dementia and something that is going to involve long term chronic deterioration in somebody, if you’re going to get a good effective support for the patient you have to get the relatives – or whoever is going to do the caring – on board as soon as possible.” *Carer, speaking on Healthtalkonline*⁴⁰⁴

7.23 The issue of trust is absolutely central in any caring relationship. Most carers provide a level of care that compromises their own health and well-being, and are concerned to help and support the person with dementia as much as they are able. This sense of duty is best captured in terms such as ‘love’, ‘loyalty’ and ‘faithfulness’, all of which are based on trust. Given this trust-based relationship between the person with dementia and their carer, there is an ethical imperative that professionals and care workers similarly start from a presumption of trust in the carer, in their good intentions and in their knowledge of the person with dementia (see also paragraph 3.12). Such trust will normally act to promote the autonomy of the person with dementia, understood in the relational sense highlighted in Chapter 2, as well as their well-being. **Unless there is evidence to the contrary, there should be a presumption of trust in carers by health and social care professionals and care workers. Such trust is a key part of any ‘caring partnership’, and without such trust it is highly unlikely that the person with dementia can be given the best possible support.** As we discussed in Chapter 6 (see paragraphs 6.39–6.45), there may sometimes be occasions when for a variety of reasons some carers do not act in the best interests of the person for whom they care, and when trust may not be appropriate. If any evidence emerges that trust in a particular carer is misplaced, the professional should act on that concern, in just the same way as they would act on concerns about other professionals or care workers. Where there are no such concerns, however, the caring partnership between carers and those paid to provide care can best be sustained, and the person with dementia best supported, through mutually trusting relationships.

Access to confidential information about the person with dementia

“I was stunned that my doctor would not speak about my concerns ... I felt frightened about my husband’s changes in behaviour ...” *Agnes Charnley, consultation respondent*

“Patient confidentiality in our system has been distorted into a charter for secrecy, when staff feel confident to deny even useful or helpful information that would support the patient’s care to other professionals or relatives.” *Professor June Andrews, Director, Dementia Services Development Centre, University of Stirling, consultation respondent*

“Sometimes families do not understand when you explain about confidentiality and they are frustrated not to be involved in consultations.” *Anonymous consultation respondent*

7.24 The Mental Capacity Act Code of Practice stipulates that health and social care staff should ensure that they only disclose information about somebody who lacks capacity if it is in the best interests of the person concerned to do so, or when there is some other, lawful reason for them to do so.⁴⁰⁵ A person granted a lasting power of attorney by the person with dementia is entitled to access

⁴⁰⁴ Healthtalkonline is a charity website that lets users share experiences of health and illness, including dementia. An interview with a carer of a person with dementia is available at: www.healthtalkonline.org/Nerves_and_brain/Carers_of_people_with_dementia/People/Interview/829/Category/102/Clip/4010/confidentiality#confidentiality.

⁴⁰⁵ Department of Constitutional Affairs (2007) *Mental Capacity Act Code of Practice* (London: The Stationery Office), paragraph 16.19.

information about the person, once they lack capacity, as long as the information is relevant to decisions they are able to make on behalf of the person.⁴⁰⁶

7.25 The Code of Practice, however, suggests that carers should not normally need to receive information from health and social care professionals about the person for whom they care, as such carers have their own knowledge of the person to guide their decisions. The Code notes that, despite the fact that a carer “will probably have good motives for wanting the information”, the professionals “might feel strongly that disclosing the information would not be in the best interests of the person who lacks capacity and would amount to an invasion of their privacy.”⁴⁰⁷ The Code therefore appears to place an emphasis on withholding information, rather than sharing it, and fails to focus on why carers *could* need information in order to help them care properly for their loved one. The Scottish Code of Practice for professionals, on the other hand, simply states briefly: “It will be necessary to consider the adult’s right to confidentiality and any previously expressed wishes about disclosure of information.”⁴⁰⁸

7.26 **We strongly support the current legal position that when a person lacks capacity, their confidential information should only be disclosed to others where it is in the best interests of the person to do so. We believe, however, that the current guidance in the Mental Capacity Act Code of Practice on when it will be in a person’s best interests to share information is too restrictive.** As we discuss in the context of diagnosis, dementia affects not only the individual with dementia, but also all those close to them, particularly those who take on the role of carer (see paragraph 3.22). When a person with dementia lacks capacity to make a particular decision about their health or welfare, it is clearly in their best interests that those involved in making the decision on their behalf have access to the necessary information and are appropriately supported. **Professionals should be made aware of the legitimate reasons why carers may ask for medical or other confidential information, and ordinarily start from the assumption that if a carer is involved in making a decision on behalf of the person with dementia, then they will need the same level of information as any other member of the care team. In short, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role.**

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

Financial and social support

“Adequate financial and emotional support for carers should be offered to ease the stress and financial hardship incurred when looking after a person who is chronically ill.” AAC Research Unit, University of Stirling, consultation respondent

7.27 Caring for a person with dementia is expensive. Costs incurred by carers include factors such as lost earnings, paying for respite and other care, and investing in adaptations and assistive technologies for the individual for whom they are caring.⁴⁰⁹ The financial impact on the household may be even more dramatic in cases of early-onset dementia where the person with dementia is the primary

⁴⁰⁶ *Ibid*, paragraph 16.9.

⁴⁰⁷ *Ibid*, paragraph 16.30.

⁴⁰⁸ Scottish Government (2007) *Adults with Incapacity (Scotland) Act 2000 Code of Practice: For persons authorised to carry out medical treatment or research under Part 5 of the Act* (Edinburgh: The Scottish Government), paragraph 1.6.7.

⁴⁰⁹ See paragraphs 6.5 to 6.12 for discussion on assistive technologies.

breadwinner in the household at the time of diagnosis. Although the benefit system in the UK includes a Carer's Allowance, this is limited to those who spend at least 35 hours a week caring for a person who receives either Attendance Allowance or Disability Living Allowance, and these benefits in turn are difficult to obtain without a formal diagnosis.⁴¹⁰ Given that over half of those with dementia do not currently obtain such a diagnosis,⁴¹¹ many carers will find it difficult to obtain financial support for this reason alone. In addition, carer organisations such as Carers UK highlight how many carers miss out on welfare benefits to which they are potentially entitled.⁴¹²

- 7.28 A carer's needs for support are not limited to financial matters, but also encompass emotional and practical support. Carers are entitled by law to a 'carer's assessment' by social services to see if they are entitled to support in their caring role, such as help in the house, adaptations, emotional support or a break from caring.⁴¹³ In a report by the House of Commons Committee of Public Accounts, however, it was noted that between half and two-thirds of all carers do not receive this assessment. In its recommendations, the Committee held that the Department of Health should "emphasise to local health organisations and their social care partners that they need to develop an action plan which gives priority to assessing and meeting the needs of carers."⁴¹⁴

Box 7.2: Example from practice – support and education for carers

Interaction training project

As part of the **Forth Valley Dementia Project**, the Dementia Services Development Centre in Stirling has developed a course to help relatives, carers and care support workers in the Falkirk area understand dementia better and improve their interaction with those for whom they care.

The course gives participants an opportunity to share experiences and consider practical ways of responding to the person with dementia. It helps participants understand what dementia is and what changes occur in the brains of those affected. It also focuses on ways of communicating and how to anticipate and deal with challenging forms of behaviour. It ends with a practical session that involves working with people to maximise communication, understand behaviours better and strengthen relationships.

More information: Dementia Services Development Centre (2008) *The Forth Valley Dementia Project* (Stirling: DSDC), p13.

Caring with Confidence

Caring with Confidence is a Department of Health backed initiative that offers free knowledge and skills-based learning for carers in England. This new programme, which is part of the Government's New Deal for Carers and the National Carers' Strategy, offers support and help to carers with particular emphasis on those who provide care on a daily basis but have difficulty finding out how to access the services and benefits available to them. It also aims to help carers to look at the essential aspects of looking after someone and how to communicate effectively with other people to help support their needs.

Carers can choose how they access the Caring with Confidence programme, either by attending face-to-face group sessions, completing self-study workbooks, accessing online sessions or a combination of all three. As part of the programme, special sessions for carers of people with dementia will be provided by the Alzheimer's Society in late 2009 in Sussex, Somerset, Devon and Hampshire.

More information: www.caringwithconfidence.net/ and http://alzheimers.org.uk/site/scripts/press_article.php?articleID=345.

- 7.29 Some carers find it very difficult to ask for the help that they need in order to cope with the situation in which they find themselves, especially where their adult identity has been based on a solid foundation of competence, capability and independence. It may take time for carers to realise that they are not coping, especially if they are making every effort to do so, and sometimes they may see asking for help as an admission of failure. Even once they have acknowledged the need for outside help, they may have difficulty in accessing it, for example because of a lack of knowledge about how the 'system' works.

⁴¹⁰ For example, Attendance Allowance and Disability Living Allowance application forms require details of the person's illness and any treatment that they receive.

⁴¹¹ National Audit Office (2007) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p7.

⁴¹² See, for example, Carers UK (2005) *Caring and Pensioner Poverty: A report on older carers, employment and benefits* (London: Carers UK).

⁴¹³ s1 Carers and Disabled Children Act 2000 in England and Wales; s9 Community Care and Health (Scotland) Act 2002; s1 Carers and Direct Payments (Northern Ireland) Act 2002.

⁴¹⁴ House of Commons Committee of Public Accounts (2008) *Improving Services and Support for People with Dementia* (London: The Stationery Office), p5.

7.30 Our emphasis on solidarity highlights society's responsibility to support people with dementia and their carers. This responsibility extends to informing carers, openly and systematically, of the social and financial support to which they are entitled: support should not only be available to those who know enough about the system and have sufficient persistence to assert their rights. We again commend the proposed role of a dementia care adviser or similar (see paragraph 3.27) who should be well placed to ensure that carers of people with dementia are better informed about their entitlements. We reiterate that a timely diagnosis (see paragraph 3.18) is also important for carers, given that without such a diagnosis carers will experience significant difficulty in obtaining the help and support they themselves need.

The help and support carers need as individuals

7.31 We have already argued that carers are individuals in their own right, and have a moral right to be treated as such (see paragraphs 2.40, 2.41 and 7.15). Carers therefore have rights for their own sake, and also, crucially, a need for support in a variety of areas.

Maintaining one's own identity

"[I] gave up teaching, singing, all things that gave me my identity." Agnes Charnley, consultation respondent

"Those caring need ... the opportunity to meet and talk about other topics, so that their whole life does not revolve around dementia." Hazel Simpson, consultation respondent

7.32 As we noted in paragraph 7.7, it takes time and reflection to acknowledge and assume for oneself both the 'role' and 'identity' of being a carer, even though that role or function may be obvious to others. Some carers may even reject their 'carer' identity altogether, and continue to see themselves as, for example, a daughter and not a carer.⁴¹⁵ Many types of adjustments are required before one can do so, especially where a diagnosis of dementia is delayed or absent.

7.33 It was also clear from our consultation that many carers face difficulties in maintaining their own identity when caring for their relative: in taking on the identity of a carer they risk losing aspects of what it meant to be themselves. It is therefore crucial that mechanisms are in place in order to allow carers to hold on to their own identity, for example through access to regular respite services in order to give them free space to be themselves and pursue their interests outside their caring role. We suggested in paragraphs 7.20 and 7.21 that carers should be seen as 'care partners' in their role of supporting the person with dementia. As a 'partner' in care, the carer should be able to feel that they are not solely responsible, and that it is legitimate for them to have some time to themselves while others provide the necessary care for their loved one.

Box 7.3: Example from practice – Falkirk 'home from home' service

The 'home from home' service is part of Falkirk Council's Joint Dementia Initiative (JDI) and involves individuals in the community welcoming people with dementia into their homes on either one or two days a week. People with dementia (living on their own or living with carers) are collected by the home owner or a member of the JDI staff and taken to the person's home. The people with dementia then spend the day choosing what they would like for meals, helping prepare the meal and carrying out other tasks such as washing the dishes. The focus is on helping people with dementia experience everyday life, from eating meals together to spending time chatting or maybe doing a crossword together, rather than attending a more institutional form of care such as a day centre. The choice of activities is up to those who attend, and the home owner and member of staff have plenty of opportunity to spend time with each person.

More information available at: <http://dementia.stir.ac.uk/pdf/folder/FVDP-HomeFromHome.pdf>. Contact details: Joint Dementia Initiative Falkirk Council, telephone: 01324 501730.

⁴¹⁵ Goldsteen M, Abma T, Oeseburg B *et al.* (2007) What is it to be a daughter? Identities under pressure in dementia care *Bioethics* 21(1): 1–12.

Box 7.4: Example from practice – carers' leisure pass

The Princess Royal Trust Salford Carers' Centre is piloting a carers' leisure pass, which gives carers unlimited access to council swimming, gym and leisure facilities. Use of the pass is monitored, and if it is not used for a continuous period of two months, the Carers' Centre is informed and the carer is contacted to check if they are well.

More information: The Princess Royal Trust for Carers (2008) *Putting People First Without Putting Carers Second* (Essex: The Princess Royal Trust for Carers), p29, available at: <http://static.carers.org/files/putting-people-first-09-individual-pages-4069.pdf>.

Counselling

"I didn't realise I was grieving. I thought you only grieved when someone was dead, and my wife isn't dead! I didn't know grieving could start with the diagnosis of a chronic illness."

Anonymous participant on family carers' course

7.34 For some carers, the option of counselling sessions may help them to understand and come to terms with some of their emotions, including possible feelings of guilt, anger and grief.⁴¹⁶ Counselling may be particularly necessary where the carer and the person with dementia have had a past emotional relationship that has been troubled or distant, although the need for counselling support may arise in any long-term caring relationship. By providing a 'safe place' where emotions can be explored in a non-judgmental way, counselling can help carers to come to terms with their own emotions about caring; support them in particular difficult situations in their caring role; and in some cases help them come to terms with the idea that other options of care should be considered.

Considering one's own interests

7.35 It is also essential that carers are supported in considering their *own* interests, as well as those for whom they care. In Chapter 5, we highlighted how, in making a particular decision for a person who lacks capacity to make that decision for themselves, others are legally required to act in that person's 'best interests'. At first sight, this suggests that the interests of the person with dementia should always be placed above those surrounding them. Yet, as we note above (see paragraph 7.14), interests are often complex and intertwined. In a family, it will rarely be the case that a single person's interests always take priority: rather some consideration will be given to everyone's interests and some degree of compromise found.

7.36 The Mental Capacity Act reflects this reality in its broad approach to 'best interests'. A determination of a person's best interests is not limited simply to what, in the abstract, might seem best for their personal welfare or well-being, but also includes consideration of factors such as their beliefs and values (see Box 5.2) and other factors they might have taken into account themselves. In many cases this will include strong concern for the welfare of others in their family. Moreover, any determination of a person's 'best interests' is inevitably limited by practical constraints, including finance and the availability of particular forms of support; and there can be no legal or ethical duty to continue caring where this is no longer physically or emotionally viable.

7.37 However, it may be very difficult for a carer genuinely to consider their own interests alongside those of the person for whom they care, even if they know that this is what the person with dementia would have wished. **Professionals such as doctors, nurses, clinical psychologists and social workers have an important role to play in supporting carers explicitly to consider their own needs and interests when weighing up difficult decisions, particularly around future care options.**

⁴¹⁶ See, for example, Alzheimer's Society (2008) *Counselling: How can it help?* Factsheet 445 (London: Alzheimer's Society), available at <http://alzheimers.org.uk/factsheet/445>; Gibson J (2009) Living with loss *Mental Health Practice* 12(5): 22–4.

7.38 It is also crucial for professionals to be aware of how carers' own needs may change significantly, to the extent that their needs may in fact be greater than those of the person for whom they care. This may particularly arise where one elderly spouse is caring for the other. Where the carer's own cognitive abilities are beginning to become impaired, professionals need to be alert both as to the carer's own needs and to the extent to which they are still capable of making decisions as a carer for the person with dementia, for example in terms of understanding the risks involved in day-to-day care. In situations where the carer is a long-standing partner, the relationship between the person with dementia and the carer may be fundamentally important to the well-being of both. In such difficult situations, it will be crucial for professionals to consider both the individual and shared priorities of care for the couple.