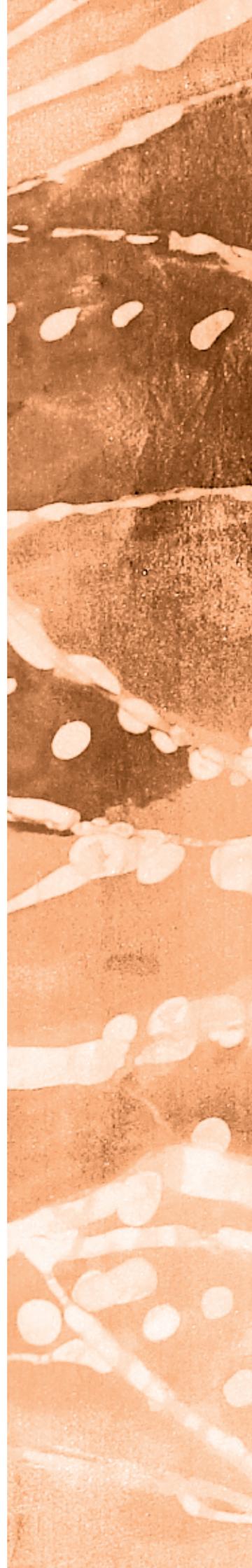


Chapter 6

Dilemmas in care



Chapter 6 – Dilemmas in care

Introduction

6.1 In Chapter 3 we considered what an ethical approach to care would look like, with a particular focus on general standards of care. In this Chapter, we consider in more detail some of the ethical dilemmas often faced by those who provide direct care to people with dementia.³¹⁹ These include whether it can be acceptable not to tell the truth; whether any form of restraint is permissible; and how freedom of action can be balanced with the need to protect the person with dementia from harm. Those facing these difficult decisions include carers, professionals and care workers, both supporting people in their own homes and working in hospitals, and residential and day care settings. The range of circumstances and different environments in which ethical questions can arise is therefore very wide. There are also many different reasons why such questions arise, including decreasing levels of capacity, changes in behaviour and mood in the person with dementia, and increased vulnerability owing to memory problems, disorientation and physical frailty.

Overview of our approach

6.2 Before discussing some examples of the individual situations and issues that give rise to ethical dilemmas we will summarise our general approach, building on our earlier discussion of approaching ethical decisions (see paragraphs 2.11 and 2.12, and Box 2.1). We consider that:

- Ethical problems arise frequently in the day-to-day care of people with dementia.
- These problems, although arising in mundane, ordinary situations, may nonetheless be problematic and stressful for those providing care.
- Many people providing care feel isolated and unsupported in making these ethical decisions.
- There is rarely one over-arching ethical value that can be used to solve an ethical problem. Critical judgment is needed. Thus, for example, although it will normally be right to tell the truth or to allow people the freedom to walk where and when they wish, there are situations where these general principles are challenged by other ethical considerations such as concerns for a person's well-being and safety or the safety of others.
- As we discuss in Chapter 2 (see paragraphs 2.7–2.12), judgment has to be applied in the light of the particular context and the details of the situation. For example, it may be wrong to tell only a partial truth in one situation but right in another similar situation because of a small but crucial difference in the context in which the decision takes place.
- There is rarely a single right answer to what should be done. There can be reasonable disagreement. Carers may quite reasonably come to different views, one from another, even where the circumstances are very similar.

6.3 As a result of these characteristics of the day-to-day ethical problems that professionals, care workers and carers may all face, our general conclusions are as follows:

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

³¹⁹ Baldwin C, Hope T, Hughes JC, Jacoby R and Ziebland S (2004) Ethics and dementia: the experience of family carers *Progress in Neurology and Psychiatry* 8: 24–8.

2. Professionals are in a position to support both carers and care workers, in addition to facing ethical problems themselves. They should have access to ongoing education to help them in both these roles. Education in ethical decision making, however, should not be limited to those with 'professional' roles: care workers are required to respond to ethical problems as part of their daily work, and should have access to the ongoing education needed to equip them to respond appropriately.
3. All those involved in direct care – carers, care workers, health and social care professionals, and volunteers – should have access to forums for sharing and receiving support in making ethical decisions. Carers and volunteers who wish to access more formal courses in ethical decision making should be able to do so.

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

Box 6.1: Example from practice – ongoing education and support relating to ethical problems

The **Bradford Dementia Group's** programme 'Cornerstones of Person-centred Dementia Care' is suitable for mixed staff groups, including care managers, nurses, therapists and support workers. The course lasts for three days, of which the third focuses on ethical problems:

Day 1: Dementia explained: the enriched model of dementia

Day 2: Therapies and interventions in dementia care

Day 3: Making difficult decisions: an ethical framework

More information: www.brad.ac.uk/acad/health/bdg/dcm/courses/cornerstone.php.

The **University of Stirling** runs two workplace training courses: one for health care assistants in hospitals, and one for care workers in care homes. Topics covered in both include "seeing the person with dementia", "communication and behaviour" and "support for the person with dementia, family and carers." Ethical quandaries are highlighted throughout the materials: for example, how do you help someone appropriately with hygiene if they refuse to have a bath? Both courses are delivered through a facilitator from the same workplace (supported by staff from the University of Stirling), with the aim of encouraging close links between the learning from the course and day-to-day practice.

More information: www.dementia.stir.ac.uk/pdf/Training-HCA-CourseFlyer.pdf and www.dementia.stir.ac.uk/pdf/Training-CHA-CourseLeaflet.pdf.

The organisation '**for dementia**' provides a six-month training programme aiming to enhance the skills of those caring for people with dementia, including care assistants, home care workers and nursing assistants. Components include person-centred care, enabling approaches to activities of daily living, and communicating with people with dementia. This accredited programme is also offered by the Dementia Services Development Centre Wales at Bangor University. One-day courses for professionals offered by 'for dementia' include person-centred communication, working with unusual behaviour, safeguarding vulnerable adults, and older people and sexuality.

More information: www.fordementia.org.uk/what-we-do/learning-partnerships-and-training/accredited-programs/.

In **Vale House**, Oxford, staff forums and handover sessions at the end of a shift are an important part of ordinary working practice. They provide a regular forum in which difficult situations arising in the home may be discussed with other colleagues, and staff can be supported in responding appropriately.

More information: www.valehouse.org.uk/.

- 6.4 In the remainder of this Chapter we will describe some of the situations highlighted in our consultation process that pose ethical challenges for all those involved in providing care for people with dementia, and suggest values and approaches that might be used in responding to them.³²⁰

Ethical dilemmas

The use of assistive technologies

"I have a tilt monitor in case I collapse and a bed monitor that alerts my wife when I have a seizure. All these devices give reassurance to my wife and family." Ross Campbell, consultation respondent

³²⁰ Further practical guidance can be found in, for example, Baldwin C, Hope T, Hughes JC, Jacoby R and Ziebland S (2005) *Making Difficult Decisions: The experience of caring for someone with dementia* (London: Alzheimer's Society) and Hughes JC and Baldwin C (2006) *Ethical Issues in Dementia Care: Making difficult decisions* (London: Jessica Kingsley Publishers).

“It makes for a better, fuller life all round for carer and sufferer.” Margaret Barbour, consultation respondent

“How would a confused person react to a disembodied voice from the wall asking why they are opening the door?!” Age Concern Leeds, consultation respondent

6.5 New technologies have the potential to make a significant difference both to people with dementia and to their family and friends who provide them with care and support. Examples include the following:

- **‘Smart’ homes** incorporate a range of technologies in order to react to the movements and activities of the person with dementia in their own home. They may include features such as automatic lighting to guide the person with dementia to the bathroom at night, automatic cut offs for taps and cookers, and presence infrared (PIR) sensors and audio prompts, such as voices instructing or reminding the person with dementia to do something.
- **Telecare** uses remote technology to monitor the health of the person and alerts an appropriate person (such as a carer sleeping in a different room or a central monitoring service) where necessary.
- **Monitoring and tracking devices** may be worn by the person with dementia, so that an alarm is sounded if the person moves away from a designated safe area, or so that the person’s exact location can be identified if they get lost.³²¹
- **Memory aids** include technological devices such as audio recordings that provide the person with reminder messages, such as “take your keys”, or “lock the door.” More sophisticated memory aids are being developed, such as cameras which automatically take hundreds of photographs a day, and which appear to stimulate the person’s memory of the events of the day.³²² Other devices may be aimed more at emotional well-being, with the use of reminiscence aids, such as those provided through the CIRCA (Computer Interactive Reminiscence and Conversation Aid) project.³²³

6.6 As these descriptions make clear, technology may play an important role in enhancing the lives of people with dementia and those who care for them. As health information and communication technologies develop, their use and usefulness is likely to increase. Devices such as memory prompts may help supplement the person’s cognitive abilities and minimise the effect of dementia on their day-to-day lives. Other technologies, such as those involved in smart homes and tracking devices, may enable people with dementia to live more freely and independently for longer, by limiting and controlling potential risks without the need for constant physical intrusion in their homes by others.³²⁴ These technologies may also be of significant benefit to carers in terms of reassurance as to the well-being and state of health of the person for whom they care. The importance of such reassurance should not be underestimated, partly in terms of reduced anxiety and hence improved quality of life for carers, and partly because of the likelihood that this in turn may enable carers to continue providing care and support for their family member for longer.

6.7 In our ethical framework, set out in Chapter 2 of this Report, we started from the assumption that, with good care, it is possible for people to ‘live well’ with dementia. We then highlighted

³²¹ See, for example, Mental Welfare Commission for Scotland (2007) *Safe to wander?* (Edinburgh: Mental Welfare Commission for Scotland); Miskelly F (2005) Electronic tracking of patients with dementia and wandering using mobile phone technology *Age and Ageing* **34**: 497–518.

³²² See, for example, Berry EL, Hampshire A, Rowe J *et al.* (2009) The neural basis of effective memory therapy in a patient with limbic encephalitis *Journal of Neurology, Neurosurgery, and Psychiatry*, published online 13 Mar 2009.

³²³ CIRCA (Computer Interactive Reminiscence and Conversation Aid) Project, available at: www.computing.dundee.ac.uk/projects/circa/.

³²⁴ Martin S, Nugent C, Wallace J *et al.* (2007) Using context awareness within the ‘smart home’ environment to support social care for adults with dementia *Technology and Disability* **19**: 143–52.

the importance of a number of factors which will be crucial in achieving that aim: first, the need to support people with dementia in a way which will enhance both their well-being and their autonomy; and, secondly, the need to consider the interests of others involved, particularly family and friends who are carers.

- 6.8 It is clear that technological devices of various types have the capacity to contribute to a person's autonomy and well-being interests. However, use of technology in these ways also has the capacity to act in ways which go *against* these interests. Concerns raised by consultation respondents about the use of assistive technologies in caring for people with dementia were mainly related to privacy, stigma (particularly with reference to tracking devices), and the worry that the use of such technology would replace, rather than be in addition to, valuable human care.³²⁵ All these issues have the potential to affect both a person's autonomy (for example through feeling controlled, being under surveillance or feeling devalued) and their well-being (for example through impoverished human relationships).³²⁶
- 6.9 It should, however, be noted that it is not so much the technologies themselves that have the potential either to promote or to harm people's interests, as the manner in which they are used.³²⁷ A monitoring device which alerts care workers that a person with dementia is moving out of a safe area of a care home may trigger very different responses. On the one hand, the person might be firmly taken back to their chair and encouraged to keep still. On the other, the care worker might respond by seeking to find out what the person wishes to do, and doing their best to assist them in achieving it. In the first case, the device may be keeping a person safe, but only by prompting restrictive action. In the second case, the device has not only kept the person safe but has also prompted support to enable the person to carry out their autonomous wishes. Even in this second, 'benign' scenario, it should be emphasised that the technological device is not a substitute for good care: rather it has the potential to *enhance* the care which the care worker is able to offer.
- 6.10 The involvement of the person with dementia in choosing or rejecting particular forms of technology is also critical. Where a person actively decides or agrees that a particular form of surveillance device will enable them to live an easier or more fulfilling life, that decision enhances their autonomy. Where a person has such a device imposed on them, either for the convenience of others or because they are seen as being incapable of being involved in the choice, then there is a far greater risk that their autonomy will be undermined. In practice, this suggests both that early discussion about the possibilities of using technology in everyday life is beneficial, and that those proposing such technology (whether carers, professionals or care workers) should do their very best to involve the person in the decision in whatever way is possible or appropriate.
- 6.11 Technology clearly has a potential role to play in supporting people with dementia and their carers to have a better quality of life, as long as the scope and limitations of any particular device are well-understood. Where the person with dementia has the capacity to choose for themselves whether to accept or refuse a particular technology, their decision should be respected. Where the person does not have capacity to make the decision, their own autonomy and well-being, along with the interests of any carers involved, must be carefully considered when coming to a decision about the appropriate use of any device or system.

³²⁵ See, for example, Nuffield Council on Bioethics (2009) *Dementia: Ethical issues – summary of public consultation* (London: Nuffield Council on Bioethics), Q23; Hughes JC, Newby J, Louw SJ, Campbell G and Hutton JL (2008) Ethical issues and tagging in dementia: a survey *Journal of Ethics in Mental Health* 3(1): 1–6.

³²⁶ Morris C (2004) Personal construct psychology and person-centred care, in *Care-Giving in Dementia: Research and applications*, Volume 3, Jones GMM and Miesen BML (Editors) (Hove: Brunner-Routledge), p67.

³²⁷ Welsh S, Hassiotis A, O'Mahoney G and Deahl M (2003) Big Brother is watching you – the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties *Aging and Mental Health* 7(5): 372–5.

6.12 Where a person with dementia lacks the capacity to decide for themselves whether to make use of a particular technology, the relative strength of a number of factors should be considered on a case-by-case basis, including:

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

Freedom of action and risk

"For fear of risk, too many people with dementia have a poorer quality of life." Barbara Pointon, consultation respondent

"My mother insisted for a long time that she could cook for herself ... having seen some burnt pans my instinct was to switch off the cooker at the mains and 'pretend' it was broken, but she delighted in being able to accomplish something for herself. An independent assessment confirmed that her sense of achievement outweighed the risks involved, with smoke detectors etc in place to try to ensure her safety as best we could." Alzheimer's Society (quoting one of its members), consultation respondent

"Anybody looking after someone with dementia would naturally make sure they are never put at risk." Anonymous consultation respondent

"The participants' first instinct in balancing protection of basic freedom and protection from harm was to find the middle ground: an action that would preserve at least the appearance or feeling of freedom whilst allowing family members to assure themselves of the person's safety." Opinion Leader, summarising the approach taken by participants in the Nuffield Council on Bioethics' Deliberative Workshop on dementia, August 2008

6.13 Taking risks is an inherent part of our everyday lives, and a life without any form of risk is unimaginable. Those caring for people with dementia however, may often feel the need to do all they can to reduce risk to an absolute minimum. This may be because of a natural tendency to be more protective of others than one is of oneself.³²⁸ It may also, in the context of care homes and other residential services, be linked with concerns about repercussions, including legal repercussions, if a person suffers harm that might have been averted.³²⁹ Unfortunately, minimising risk often means forgoing benefits and restricting freedom, which in turn may be highly detrimental both to the person's sense of autonomy and to their overall well-being.

6.14 It was clear from our consultation responses that the issue of how best to balance freedom and protection for a person with dementia causes much anxiety among carers. Research by the American Alzheimer's Association showed that this issue is also important to people with early-stage dementia. In particular, much anger was expressed by research participants about attempts to control their behaviour and minimise risk in a way which they saw as both excessive and demeaning.³³⁰ In later stages of dementia, it is sometimes argued that 'difficult' or 'unusual'

³²⁸ See, for example, evidence about research involvement where proxies tend to be more protective than the person would have been themselves, including Muncie HL Jr, Magaziner J, Hebel JR and Warren JW (1997) Proxies' decisions about clinical research participation for their charges *Journal of the American Geriatric Association* 45: 929–33.

³²⁹ See, for example, the discussion of the 'duty of care' owed to people living in residential care in Commission for Social Care Inspection (2007) *Rights, Risks and Restraints: An exploration into the use of restraint in the care of older people* (London: Commission for Social Care Inspection), at p50, where it is emphasised that a 'duty of care' does not mean keeping people safe from every possible risk.

³³⁰ Alzheimer's Association (2008) *Voices of Alzheimer's Disease* (Chicago: Alzheimer's Association), p17.

behaviours on the part of the person with dementia are often a response to what is perceived as over-controlling and restrictive behaviour on the part of the carer.³³¹

- 6.15 Dilemmas relating to risk taking and freedom of action arise throughout dementia, from when early symptoms first appear to much later stages. The question of whether a person with early dementia should continue driving, for example, can be highly problematic. This involves balancing likely risks to both self and others with the freedom of the person with dementia.³³² The Alzheimer's Association research identified how very differently individuals respond to what many experience as a major blow to their independence: some give up driving almost immediately, while others continue as long as possible and strongly resist suggestions that they are not safe.³³³ Later in dementia, the balance between facilitating a person's wishes and protecting their safety may arise in terms of safe walking outside,³³⁴ or when considering how to meet a person's desire for privacy in the bathroom despite concern about the danger of falling. Similar concerns arise at all stages of dementia in terms of independent living.
- 6.16 These dilemmas arise in part because there may be conflicts between the autonomy interests of people with dementia, their own well-being interests, and the interests and safety of others. There may, furthermore, be conflicts even when considering only one interest. For example, although high levels of physical safety are an important aspect of well-being, the constraints, lack of privacy and lack of variety in life which may often accompany protective measures may significantly interfere with well-being. It may be valuable to recognise, too, that 'feeling safe' contributes to well-being.³³⁵
- 6.17 In recognising that a balance must be struck between enabling a person to live their life in the way they wish, promoting their well-being, protecting their safety, and protecting the safety and interests of others, we would like to emphasise the following points:
- Risks cannot be avoided completely. Some degree of risk is inevitable in everyday living.
 - Encouraging independence and freedom of action is an important part of providing good quality of care and of supporting a person's autonomy. Restrictions that limit these freedoms may have an adverse effect both on the person's autonomy and on their general well-being, even where they are imposed with the aim of protecting the person.
 - It is clearly important that those providing care for people with dementia assess and manage risk appropriately, and care providers are accordingly required to carry out 'risk assessments' for all those in their care.³³⁶ However, the nature of a 'risk assessment' is such that it is very easy to focus only on the possible risks and how they can be minimised or eliminated, without considering what opportunities and benefits are being forgone as a result. For this reason we believe that 'risk assessment' is a misguided term and should be replaced by 'risk-benefit assessment'.

³³¹ See, for example, Stokes G (2007) *Challenging Behaviour in Dementia: A person-centred approach* (Brackley, UK: Speechmark Publishing Ltd.); the point was also made at the Working Party's fact-finding meeting with people on the front-line of dementia care, 10 July 2008.

³³² Drivers' Medical Group, Driver and Vehicle Licensing Agency (2009) *For Medical Practitioners: At a glance guide to the current medical standards of fitness to drive* (Swansea: Driver and Vehicle Licensing Agency); Alzheimer's Society (2008) *Driving and Dementia*, Factsheet 439 (London: Alzheimer's Society), available at: <http://alzheimers.org.uk/factsheet/439>.

³³³ Alzheimer's Association (2008) *Voices of Alzheimer's Disease* (Chicago: Alzheimer's Association), p16.

³³⁴ Robinson L, Hutchings D, Corner L *et al.* (2007) Balancing rights and risks: conflicting perspectives in the management of wandering in dementia *Health, Risk & Society* 9(4): 389–406.

³³⁵ Qureshi H and Henwood M (2000) *Older People's Definitions of Quality Services* (York: Joseph Rowntree Foundation), available at: www.jrf.org.uk/sites/files/jrf/185935338x.pdf.

³³⁶ The Regulation and Quality Improvement Authority (2008) *Residential Care Homes: Minimum standards* (Belfast: Department of Health, Social Services and Public Safety), standard 3.4; The Scottish Government (2007) *National Care Standards: Care homes for older people* (Edinburgh: The Scottish Government), standards 3, 4, and 9; Welsh Assembly Government (2004) *National Minimum Standards for Care Homes for Older People* (Cardiff: Welsh Assembly Government), standard 6.3; Department of Health (2003) *Care Homes for Older People: National minimum standards – care homes regulations* (London: The Stationery Office), standard 3.3.

- A 'risk-benefit assessment' considers both the possible risks and the potential benefits of a proposed activity, service or facility. The one can then be weighed against the other, enabling some risk to be accepted in order to achieve a particular benefit.
- Such an approach encourages those providing care to consider what is best for *this* particular person (taking into account others' safety and interests where appropriate), rather than simply choosing the course of action which, in the abstract, appears to pose the lowest level of risk. It also discourages an approach to risk which is based more on the convenience of others than on the needs of the person with dementia. A risk-benefit assessment further encourages the person carrying it out to consider the risks of *not* providing or permitting the activity in question: for example the risks of walking outside or alone should be weighed against the risks of prolonged sitting, boredom and frustration.
- The importance of considering risks and benefits together is also relevant when considering the well-being of a group of people. Facilities such as kitchenette areas in care home lounges, encouraging more independence and a more home-like feel, or ornamental pools in care home gardens, may have a significant part to play in the quality of life of people living in the home, and such benefits must be taken properly into account when assessing and managing any risks they might also pose.

Recommendation 10: We recommend that the UK Departments of Health and the four bodies regulating adult social care in the UK³³⁷ should require care providers to consider risks not in isolation but in the context of a risk-benefit assessment. Such risk-benefit assessments should explicitly take into account the well-being and autonomy of the person with dementia, as well as their need for protection from physical harm and the needs and interests of others. The term 'risk assessment' should be replaced by 'risk-benefit assessment' in order to highlight the importance of benefits which may be lost in the attempt to reduce risk.

6.18 We recognise that those providing paid care in either residential or home settings are potentially subject to criticism, and even legal action, if a person with dementia suffers harm as a result of a particular decision taken to promote their independence or freedom of action. These concerns might understandably lead to cautious decisions being taken that err on the side of excessive restriction of freedom in the name of safety. We suggest that a focus on *benefits*, as well as risks, as discussed above, together with good communication between professionals, care workers and families, should help in making decisions which best support the person with dementia to have a good quality of life. Such discussions should, wherever possible, include the person with dementia themselves.

Sexual relationships and sexual disinhibition

"Healthcare services need to take on board that people still have sex over the age of retirement and build this into assessment and care needs for people, including the privacy and intimate space to have mutually consenting sexual relationships." *United Kingdom Psychiatric Pharmacy Group and The College of Mental Health Pharmacists, consultation respondents*

"Should I allow this person with dementia privately to have a [new] sexual relationship, or should I tell the family to allow them to decide to forbid it?" *Professor June Andrews, Director, The Dementia Services Development Centre, University of Stirling, consultation respondent*

³³⁷ The Care Quality Commission in England; the Care and Social Services Inspectorate Wales; the Care Commission in Scotland; and the Regulation and Quality Improvement Authority in Northern Ireland.

- 6.19 Intimate sexual relationships often continue into old age, with research showing that many men and women remain sexually active well into their eighties.³³⁸ Little, however, is yet known about how couples where one or both partners have dementia make adjustments to accommodate their sexual relationship as the dementia progresses, or about the effects of specific types of dementia on the ability to engage in a sexual relationship. Respect for both a person's autonomy and their well-being demands that such relationships should be respected. Neither carers nor care workers should make the assumption that the sexual aspect of a long-standing relationship between a person with dementia and their partner is no longer important or consensual, and care homes in particular should take steps to ensure that their residents have the privacy to continue such relationships to the extent that they wish. While the rational ability of a person to consent to sexual activity is likely to decline as dementia progresses, it would be quite inappropriate for professionals to intervene in a relationship of a long-standing consensual nature, unless there are genuine concerns as to the willingness of one partner to participate.³³⁹
- 6.20 Difficulties can arise, however, where the relationship in question is new, or relatively new. These may include concerns about the consensual nature of the relationship and the difficulties that some members of the individual's family may face in dealing with the fact that their relative has a desire to form a new relationship in a care home context.³⁴⁰ Depending on the degree of cognitive impairment on either side, such relationships may reflect genuine attraction between two individuals (including where a spouse is still alive); they may be based on mistaken beliefs on one or both sides (for example that the other person is in fact their spouse); or they may potentially be abusive. In some circumstances, however, what looks like a 'sexual relationship' may in fact simply be the result of disorientation: a person with dementia may simply have gone into the wrong bedroom and unwittingly got into bed with the occupant.
- 6.21 Deciding if, when, and how to intervene in a new sexual relationship may be very difficult, and a case conference involving relevant care workers and professionals may be a useful way of coming to a decision. If it is clear that the relationship is unwanted, or harmful, for one of the people involved, then that person should be appropriately protected. If this is not the case, then, while it will often be appropriate to involve family members who know the person well, their distaste for the idea of a new relationship starting late in life should not be sufficient reason for intervening. Any decision must be made on the basis of the person's own autonomy and well-being, bearing in mind that the person's own past views about sexual fidelity will be an important part of assessing their autonomy interests.
- 6.22 It is also crucial for those providing care to be aware that some people with dementia (7% in one survey³⁴¹ but less than 2% in another³⁴²) may behave in a way that is seen as sexually 'inappropriate' or ambiguous, for example through exposing themselves in public, making sexually explicit comments, or inappropriate touching. Such behaviour may result from the damage to parts of the brain which control and inhibit behaviour which would normally be kept private (see paragraph 1.8), or may simply be linked with the person's disorientation in time or space: for example a person may expose themselves in public because they need to go to the toilet and not for any

³³⁸ Tessler Lindau S, Schumm LP, Laumann EO *et al.* (2007) A study of sexuality and health in older adults in the United States *New England Journal of Medicine* **357**: 762–74.

³³⁹ For a more detailed discussion of this issue, see Bouman WP (2008) Sexuality in later life, in *Oxford Textbook of Old Age Psychiatry*, Jacoby R, Oppenheimer C, Denning T and Thomas A (Editors) (Oxford: Oxford University Press), pp689–707.

³⁴⁰ Ehrenfeld M, Bronner G, Tabak N *et al.* (1999) Sexuality among institutionalised elderly patients with dementia *Nursing Ethics* **6(2)**: 144–9.

³⁴¹ Burns A, Jacoby R and Levy R (1990) Psychiatric phenomena in Alzheimer's disease IV: disorders of behaviour *British Journal of Psychiatry* **157**: 86–94.

³⁴² Alagiakrishnan K, Lim D, Brahim A *et al.* (2005) Sexually inappropriate behaviour in demented elderly people *Postgraduate Medical Journal* **81**: 463–6.

sexual motivation.³⁴³ It has been noted that there will often be a fine line between ‘appropriate’ and ‘inappropriate’ behaviour, depending on the values and concerns of those working in the care home and family members, and that it is important to avoid stereotypical assumptions of older adults as asexual.³⁴⁴ It is also clearly inappropriate to label behaviour as ‘sexual’ when in fact it arises out of discomfort, disorientation or toileting difficulties. Where behaviour is genuinely sexually inappropriate, professionals and care workers should feel confident in managing it in a consistent way, while seeking to treat the person concerned with respect.³⁴⁵

Truth telling

“I felt fully justified in telling lies if it prevented my mother going through even more distress.” Mrs Linda Tolson, consultation respondent

“I don’t think it helps anyone to lie about anything.” Anonymous consultation respondent

“There comes a point when conversation is more important than cold truth and a conversation about a person is more constructive than living through bereavement day after day.” Older People and Disability Team, Social Care and Learning Department, Bracknell Forest Council, consultation respondent

“[A] sensible balance of truth and ‘white lies.’” Anonymous consultation respondent

- 6.23 As the quotes above suggest, responses to the consultation question on the subject of truth telling ranged from an absolute prohibition on telling lies, to viewing well-being as paramount. Other responses portrayed the anguish relatives of people with dementia experience in trying to do the ‘right thing’, and highlighted that, in many cases, the difference between ‘the truth’ and a ‘white lie’ may not be as clear as first appears.
- 6.24 The ethical reasoning behind most responses was based on concern for the well-being of the person with dementia, with conflicts experienced between the desire to maintain trust (especially in the context of long-standing relationships built on trust) and avoiding distress. These considerations of the interests of the person with dementia run alongside both beliefs about the moral importance of telling the truth and practical concerns about how to get through the day.
- 6.25 The issue of truth telling highlights the difficulties inherent in determining what course of action is genuinely in a person’s best interests, both in the immediate and longer term. Avoiding distress is clearly important for the person’s day-to-day happiness, while many will feel strongly that ‘not being lied to’ is an important aspect of the more objective elements of a person’s well-being and autonomy interests. Questions of trust are particularly difficult. Some argue that failing to tell the truth is a breach of trust and serves to undermine the remaining grip the person with dementia may have on the everyday world.³⁴⁶ Others point out that telling the straightforward truth in circumstances where the person with dementia will not believe it may equally undermine trust because the person will think that they are being lied to.³⁴⁷ For care workers and professionals there is the added issue of whether telling lies undermines the integrity of professional care,³⁴⁸ and

³⁴³ See, for example, Stokes G (2007) *Challenging Behaviour in Dementia: A person-centred approach* (Brackley, UK: Speechmark Publishing Ltd), at p17 and p113.

³⁴⁴ Bouman WP (2008) Sexuality in later life, in *Oxford Textbook of Old Age Psychiatry*, Jacoby R, Oppenheimer C, Denning T and Thomas A (Editors) (Oxford: Oxford University Press), pp689–707, at 701.

³⁴⁵ See, for example, Ballard C, O’Brien J, James I and Swann A (Editors) (2001) *Dementia: Management of behavioural and psychological symptoms* (Oxford: Oxford University Press), p279.

³⁴⁶ Schermer M (2007) Nothing but the truth? On truth and deception in dementia care *Bioethics* 21(1): 13–22.

³⁴⁷ Working Party’s fact-finding meeting with Professor Dawn Brooker from the Bradford Dementia Group, 30 Sept 2008.

³⁴⁸ Schermer M (2007) Nothing but the truth? On truth and deception in dementia care *Bioethics* 21(1): 13–22.

for all concerned in providing care, paid or unpaid, there is the concern that failing to tell the truth is detrimental to their own moral well-being.

- 6.26 As we made clear at the beginning of this Chapter, we do not believe that there is a single answer to this dilemma. Telling the truth is clearly an important moral value, and telling the truth will always be the natural starting point. However, in circumstances where significant distress or anger is caused by verbally truthful answers to questions, because of the person's cognitive problems, then it may be more humane to find responses that evade or offer only a partial answer to the person's question, in order to minimise distress. Only very rarely would a direct lie be the best or only option.
- 6.27 In many cases it may also be appropriate to seek to respond to the *emotions* involved, even if this involves some degree of latitude with the factual truth. Indeed, it could be argued that such an approach is truthful, in that it responds to the *actual* concerns of the person with dementia, regardless of the language in which it is clothed. One carer, for example, described to us how he would always tell his wife that he was 'going shopping' at the end of a visit to her care home, because she understood that to mean that he was going but would be back sometime soon. Saying a simple 'goodbye', on the other hand, caused significant distress, presumably because it was interpreted as indicating a much longer separation than would in fact be the case.³⁴⁹

Restraint

"I remember the University of – somewhere – hospital, I got so agitated that they had to strap me down ... I did hate that ... I remember that night as one of the very worst nights in all the time I've lived."³⁵⁰

"My father was moved without warning from one acute ward to another, and he naturally became distressed, and complained loudly. The reaction of the nurses was to surround him with furniture, and get security staff to stand over him." *Anonymous consultation respondent*

"... sometimes it is essential. What else would you do if a patient was assaulting another patient?" *Anonymous consultation respondent*

- 6.28 The issue of restraint often arises in the context of dementia, either because restraint is seen as a possible way of protecting the person with dementia (for example with the aim of preventing them from falling) or because of concerns about the safety of others (for example where the person with dementia is perceived to be acting in a threatening way). In some circumstances, the person with dementia may have the capacity to understand why a particular restraint is being suggested for their own safety and may consent to its use. Such uses of restraint are usually unproblematic. However, in many cases the person with dementia may not be in a position to consent, or restraint may be used in order to control behaviour that others find difficult or alarming, and in such cases restraint may be experienced as highly demeaning and distressing. Yet, at times, those caring for a person with dementia may see no alternative but to use restraint.

Uses of restraint

- 6.29 The most obvious form of restraint is *physical restraint*. This may involve force, for example to control someone who is behaving aggressively; alternatively it may include equipment such as straps or lap belts. Less overt forms of restraint include placing a person in a chair which is too low

³⁴⁹ Bruce Bovill, responding to the Working Party's consultation.

³⁵⁰ Henderson CS (1998) *Partial View: An Alzheimer's journal* (Dallas: Southern Methodist University Press), p88.

for them to get out of without help, or locking doors to prevent people from leaving a room or building.³⁵¹ There may be significant physical and emotional risks of being physically restrained, coupled with a risk that restraint will become a vicious circle, with the distress and reaction to restraint putting a person at a greater risk of being repeatedly physically restrained in the future.³⁵² There is also the risk that physical restraint imposed with the aim of avoiding minor accidents may in fact lead to more serious outcomes, such as more serious accidents if a person tries to move despite the restraint mechanism, reduced mobility, pressure sores and depression.³⁵³

- 6.30 A number of pharmacological treatments, including anti-depressants, anti-anxiety medicines, mood-stabilising medicines and anti-psychotics may be used to calm and control the behaviour of a person with dementia by reducing their levels of activity or consciousness. Where these medicines are used primarily with the aim of controlling behaviour, rather than responding to symptoms such as anxiety or depression, this is sometimes known as *chemical restraint*.
- 6.31 Much has recently been written about the way the anti-psychotic drugs, in particular, have been overused in people with dementia,³⁵⁴ and this is of particular concern given evidence that use of anti-psychotic medicines in people with Alzheimer's disease and dementia with Lewy bodies is associated with a shortened life expectancy.³⁵⁵ The NICE/SCIE guidelines make clear that medication should be considered for 'behaviour that challenges' in the first instance only if there is severe distress or immediate risk of harm, with non-pharmacological approaches preferred in all other circumstances (see Box 1.2). However, it is important to keep a clear distinction between when these medicines are being used in response to particular symptoms, and when they are being used in the very short term as a form of restraint, as an alternative to physical restraint. In the first case, their use should be governed by the best practice guidance issued by NICE/SCIE and SIGN, while in the latter case they will additionally be governed by the law on restraint outlined below.

The law on restraint

"In drawing attention to the issue the law raises awareness of the undesirability of restraint but it provides little guidance as to the level and nature of appropriate restraint or circumstances in which it might be used." Dr Hazel McHaffie, consultation respondent

- 6.32 In England and Wales, the Mental Capacity Act governs cases where a person who lacks capacity is restrained by others. It allows restraint to be used only when it is necessary to prevent harm to the person lacking capacity and where it is a "proportionate" response to the likelihood of the person suffering harm, and to the seriousness of that harm.³⁵⁶ The Act uses a wide definition of 'restraint': "the use or threat of force to help do an act which the person resists, or the restriction of the person's liberty of movement, whether or not they resist."³⁵⁷ An authoritative commentary

³⁵¹ Depending on the circumstances (for example the time-scale involved, and the degree of control exerted over the person concerned), locking people in a room or building may in fact constitute 'deprivation of liberty', rather than restraint, and will be subject to additional safeguards.

³⁵² Wang W and Moyle W (2005) Physical restraint use on people with dementia: a review of the literature *Australian Journal of Advanced Nursing* **22(4)**: 46–52.

³⁵³ Commission for Social Care Inspection (2007) *Rights, Risks and Restraints: An exploration into the use of restraint in the care of older people* (London: Commission for Social Care Inspection), p51.

³⁵⁴ See, for example, All Party Parliamentary Group on Dementia (2008) *Always a Last Resort: Inquiry into the prescription of anti-psychotic drugs to people with dementia living in care homes* (London: Alzheimer's Society); Alldred DP, Petty DR, Bowie P, Zermansky AG and Raynor DK (2007) Antipsychotic prescribing patterns in care homes and relationship with dementia *Psychiatric Bulletin* **31(9)**: 329–32; Fossey J, Ballard C, Juszcak E *et al.* (2006) Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial *British Medical Journal* **332**: 756–61.

³⁵⁵ Ballard C, Hanney ML, Theodoulou M *et al.* (2009) The dementia antipsychotic withdrawal trial (DART-AD): long-term follow-up of a randomised placebo-controlled trial *Lancet Neurology* **8(2)**: 151–7; McKeith I, Fairbairn A, Perry R, Thompson P and Perry E (1992) Neuroleptic sensitivity in patients with senile dementia of Lewy body type *British Medical Journal* **305**: 673–8.

³⁵⁶ ss6(2) and 6(3) Mental Capacity Act 2005, emphasised further in the Mental Capacity Act 2005 Code of Practice, chapter 6.41.

³⁵⁷ s6(4) of the Mental Capacity Act, as summarised in the Mental Capacity Act 2005 Code of Practice, p290.

on the Act suggests that this may include many forms of restraint, both verbal and physical, “from shouting at someone, to holding them down to locking them in a room” and may also include “the prescribing of a sedative or other chemical restraint which restricts liberty of movement.”³⁵⁸ The Act clearly prohibits those providing care from restraining people with dementia simply in order to make their own tasks easier: there must be an objective reason for the restraint in order to prevent harm to the person with dementia. Moreover, the restraint must be “proportionate”, that is, the need for the restraint must be sufficiently serious to justify such a serious response, and if less intrusive ways of dealing with the situation can be found, these should be preferred.

- 6.33 The Adults with Incapacity (Scotland) Act is silent on the issue of restraint in general, but states that “force and detention” may be used in connection with medical treatment only where it is immediately necessary.³⁵⁹ As in England, the common law permits restraint if this is necessary to prevent immediate harm or in self-defence.³⁶⁰ In all four countries of the UK, the regulations governing care homes forbid restraint unless it is “the only practicable means of securing the welfare of that or any other service user and there are exceptional circumstances.”³⁶¹ Detailed guidance issued by the Mental Welfare Commission for Scotland makes clear that in Scotland this requirement should be interpreted as meaning that restraint should only ever be a “last resort, where there is absolutely no alternative.”³⁶² The Northern Ireland consultation document setting out broad proposals for a new Mental Capacity Act states that the new legislation will make clear that “restraint will only be permitted if the person using it reasonably believes it is necessary to prevent harm and it is proportionate to the likelihood and seriousness of the harm.”³⁶³
- 6.34 While the various Regulations governing the use of restraint in care homes in England, Wales, Scotland and Northern Ireland all limit the use of restraint to “exceptional” circumstances, where there is no alternative course of action, there is considerable anecdotal evidence that, in fact, restraint is much more widely used than this. An ‘exploration’ of restraint in English care homes, carried out in 2007 by the Commission for Social Care Inspection (CSCI), described many examples of restraint which appeared to be routine rather than exceptional, and the Commission cited “widespread suspicion” that restraint was often used not to ensure residents’ safety but in order to help staff manage their workload.³⁶⁴ Thus, although the Regulations are clear as to the exceptional nature of restraint, it is less clear that they are being respected in practice.
- 6.35 CSCI concluded its report with a set of principles which good restraint policies in care homes should include, emphasising that restraint should always “be the least restrictive option and undertaken for the shortest viable length of time”, and recommended that its successor body (the Care Quality Commission) should continue to keep the issue of restraint under review. The guidance published by the Mental Welfare Commission in Scotland, on the other hand, is much more detailed, setting out

³⁵⁸ Ashton G, Letts P, Oates L and Terrell M (2006) *Mental Capacity: The new law* (Bristol: Jordans), paragraph 2.133.

³⁵⁹ s47(7)(a) Adults With Incapacity (Scotland) Act 2000.

³⁶⁰ A summary of the common law is given in Mental Welfare Commission for Scotland (2006) *Rights, Risks and Limits to Freedom: Principles and good practice guidance for practitioners using restraint in residential care settings* (Edinburgh: Mental Welfare Commission for Scotland), Appendix 1.

³⁶¹ Regulation 13(7)(a) of the Care Homes Regulations 2001, SI 2001/3965, as amended; Regulation 4(1)(c) of the Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002, SSI 2002/114, as amended; Regulation 14(5) of the Residential Care Homes Regulations (Northern Ireland) 2005, SR2005/161, as amended; Regulation 13(7) of the Care Homes (Wales) Regulations 2002, SI 2002/324(W.37), as amended.

³⁶² Mental Welfare Commission for Scotland (2006) *Rights, Risks and Limits to Freedom: Principles and good practice guidance for practitioners using restraint in residential care settings* (Edinburgh: Mental Welfare Commission for Scotland), p2.

³⁶³ Northern Ireland Department of Health, Social Services and Public Safety (2009) *Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland: A policy consultation document* (Belfast: Northern Ireland Department of Health, Social Services and Public Safety), paragraph 5.1.

³⁶⁴ Commission for Social Care Inspection (2007) *Rights, Risks and Restraints: An exploration into the use of restraint in the care of older people* (London: CSCI), pp39–40.

practical requirements which encourage the use of restraint only as a genuine exception to the norm. One example is the requirement that members of staff must be “in direct visual and verbal contact with the resident” during any time in which their movements are subject to restraint, thus automatically preventing the use of restraint as a way of dealing with staff shortages or pressures.³⁶⁵

Our approach

- 6.36 The issue of restraint, and when it is right to use it, will usually involve the balancing of several values (see paragraph 6.2). Clearly there have to be very good reasons to justify the use of restraint, and by specifically restricting the use of restraint to circumstances where it is “proportionate”, the Mental Capacity Act highlights this point, as does the detailed guidance issued by the Mental Welfare Commission for Scotland. The regulations governing care homes throughout the United Kingdom arguably go further by emphasising the exceptional nature of restraint, although, as we note above, there is some evidence that these requirements are not reliably followed.
- 6.37 We note, however, that it is far from clear in many circumstances how the ‘proportionality’ principle in the Mental Capacity Act would work in practice, and that this lack of clarity poses real difficulties for those providing care, particularly carers, on a regular basis. For example, is it proportionate for a wife who cares alone for her husband with dementia to lock him in the house or in the car while she goes shopping, because she is not able to obtain any support to look after him in her absence and he might be at risk if he went out alone? Is it proportionate for her to leave him in a low chair which he cannot leave without help, in order to cook a meal in peace? Sometimes the real issue at stake is the availability of support for carers: what is needed is not reassurance about the proportionality of the form of restraint, but rather a sitting service for a few hours a week and some assistance in identifying activities which will occupy the person with dementia without the need for restraint. In many cases, however, such support will simply not be available, and there will always be less predictable circumstances or emergencies where a planned solution is unlikely to be applicable.
- 6.38 We have emphasised, throughout this Report, the equal value of people with dementia, the importance of promoting their autonomy and well-being, and the moral importance of demonstrating solidarity both with people who have dementia and with the family and friends who support them. We recognise that restraint is an immensely difficult and emotional issue that is often experienced as deeply degrading and de-humanising, and yet there may be times when carers feel they must use restraint. We suggest our focus on solidarity provides strong justification for the argument that support for carers that obviates the need for restraint should be regarded as a very high priority by local health and social services. While the Mental Capacity Act Code of Practice contains some useful advice about when the use of restraint is “proportionate”, we also suggest that more explicit guidance, covering a much wider range of situations in the context of the home, would be very helpful.

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

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

³⁶⁵ Mental Welfare Commission for Scotland (2006) *Rights, Risks and Limits to Freedom: Principles and good practice guidance for practitioners using restraint in residential care settings* (Edinburgh: Mental Welfare Commission for Scotland), paragraph 3.1.19.

Recommendation 13: We further recommend that the UK Health Departments should draw specific attention to the importance of providing support to carers that will minimise the need for restraint in the domestic context, for example through guidance to health and social services organisations on needs assessment.³⁶⁶

Abuse by family or friends

“Should I respond to an apparent abuse of the patient by the carer, or do I remain silent, as the alternative institution is probably unpleasant and not what the patient would have wanted?” Professor June Andrews, Director, Dementia Services Development Centre, University of Stirling, consultation respondent

“[There is a] difficulty of establishing whether or not abuse has taken place, in the person’s own home or in a care home.” Guideposts Trust, consultation respondent

- 6.39 It is only relatively recently that the abuse of older people, both by their carers and by professionals or care workers, has been recognised as a serious issue.³⁶⁷ It has since been shown that cognitive impairment is itself a significant risk factor for abuse,³⁶⁸ and hence older people with dementia may be particularly vulnerable. The abuse of people with dementia by the family or friends involved in caring for them raises particular ethical issues, because of the complex relationships and dependencies involved, and this section will focus specifically on this aspect of abuse.
- 6.40 A clear picture of the scale either of elder abuse in general, or of the abuse of people with dementia in particular, remains elusive, in part because of varying definitions of elder abuse. In 2002, in its Toronto Declaration on the Global Prevention of Elder Abuse, the World Health Organization (WHO) adopted the definition used by the UK organisation Action on Elder Abuse: “a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person”, and noted that it can be of various forms: “physical, psychological/emotional, sexual, financial or simply reflect intentional or unintentional neglect.”³⁶⁹ By contrast, other definitions emphasise the intent of the person perpetrating the abuse, or limit the definition to ‘harm or a serious risk of harm’, rather than the wider ‘harm or distress.’³⁷⁰ An overview published in 2008 of empirical studies of ‘maltreatment’ of people with dementia by carers, covering factors such as emotional or verbal abuse, financial exploitation, and various forms of neglect and violence, cited figures of physical abuse of the person with dementia of between five per cent and 12 per cent (47% where the research was carried out among those being referred for respite care) and emotional abuse of between 11 per cent and 52 per cent.³⁷¹

³⁶⁶ See, for example, the guidance issued by the Department of Health in England on the ‘single assessment process’, available at: www.dh.gov.uk/en/SocialCare/Chargingandassessment/SingleAssessmentProcess/DH_079509.

³⁶⁷ See, for example, Baker AA (1975) Granny battering *Modern Geriatrics* 8: 20–4 and Burston GR (1975) Granny battering *British Medical Journal* 3: 592, both cited in Cooney C and Wrigley M (1996) Abuse of the elderly with dementia *Irish Journal of Psychological Medicine* 13(3): 94–6.

³⁶⁸ Cooney C and Wrigley M (1996) Abuse of the elderly with dementia *Irish Journal of Psychological Medicine* 13(3): 94–6; Hirsch RD and Vollhardt BR (2008) Elder maltreatment, in *Oxford Textbook of Old Age Psychiatry*, Jacoby R, Oppenheimer C, Dening T and Thomas A (Editors), pp731–45 at 735.

³⁶⁹ World Health Organization (2002) *The Toronto Declaration on the Global Prevention of Elder Abuse* (Geneva: World Health Organization); also see Action on Elder Abuse (2008) *What is Elder Abuse?* (London: Action on Elder Abuse), available at: www.elderabuse.org.uk/Useful%20downloads/leaflets/whatisleaflet.pdf.

³⁷⁰ See, for example, the definition used by the National Center on Elder Abuse: “any knowing, intentional, or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable adult”, available at: www.ncea.aoa.gov/NCEARoot/Main_Site/FAQ/Questions.aspx.

³⁷¹ Hirsch RD and Vollhardt BR (2008) Elder maltreatment, in *Oxford Textbook of Old Age Psychiatry*, Jacoby R, Oppenheimer C, Dening T and Thomas A (Editors) (Oxford: Oxford University Press), pp731–45, table 39.3.

- 6.41 The WHO definition of elder abuse is valuable in that it highlights the wide range of contexts in which harm may occur to older people. It should, however, be emphasised that since this definition has been interpreted as including behaviours such as using a harsh tone or insulting the person with dementia, or threatening to send them to a care home, the figures on abuse must also be interpreted in this light. For example, a 2009 survey of abuse of people with dementia by carers, using the WHO definition of 'abuse', was widely reported as showing that over half the carers of people with dementia were guilty of abuse.³⁷² In the detailed breakdown of forms of abuse included in the study, however, the percentage of carers who admitted physical abuse was one per cent of those participating in the study, with a further three per cent saying that they had been afraid they might hit or hurt the person for whom they were caring, but had not done so. Thirty-three per cent of carers, on the other hand, reported behaviours that the authors categorised as 'psychological' abuse at least sometimes in the previous three months: these behaviours including screaming or swearing at the person for whom they cared, and threatening to stop caring for them or send them to a care home.
- 6.42 It is clearly very important to make the point that abuse can take many different forms, and that repeated verbal abuse and threats may be as harmful and distressing as physical violence. Moreover, studies such as the 2009 research cited above may underestimate serious cases of physical abuse, or malicious forms of abuse, which people are reluctant to acknowledge. Nevertheless, this study does suggest that headline figures about the prevalence of abuse in dementia should be treated with caution. The nature of the distress, the intent of those causing the distress, and the background circumstances will all be important factors in determining how best to combat the abuse. Moreover, while physical violence will always be a source of immediate concern, it is important to note that the distress caused by what is described as 'psychological' abuse will vary enormously: in some households a husband and wife may always have shouted at each other, and may continue to do so without harm, while in others the person with dementia may experience significant distress from raised or angry voices.
- 6.43 The Alzheimer's Society has noted that, in many cases, behaviour which is distressing or harmful to the person with dementia may be unintentional, perhaps due to a lack of understanding about dementia and its impact, and not because the carers of the person with dementia are cruel or malicious.³⁷³ In other cases the harm or distress may result from excessive stress on carers, owing to exhaustion, ill-health and lack of support, especially where behaviour on the part of the person with dementia may sometimes be deeply frustrating, threatening,³⁷⁴ or indeed violent.³⁷⁵ In some cases, these problems will be exacerbated by an already poor relationship between the person with dementia and a family member who has felt coerced into taking on the role of carer. The need to intervene in order to protect the person with dementia remains the same, regardless of the intent of the person causing the harm; however, the action necessary to protect the person may be quite different.
- 6.44 When professionals suspect that a person with dementia is suffering harm from a carer or other family member or friend, they have both a legal and an ethical duty to act to protect the person

³⁷² Cooper C, Selwood A, Blanchard M *et al.* (2009) Abuse of people with dementia by family carers: representative cross sectional study *British Medical Journal* **338**: b155; Daily Express (23 Jan 2009) *Dementia sufferers abused – survey*, available at: www.express.co.uk/posts/view/81349; The Guardian (23 Jan 2009) *Over 50% of carers admit to elder abuse*, available at: www.guardian.co.uk/society/2009/jan/23/elder-abuse-dementia.

³⁷³ Alzheimer's Society (2008) *Uncovering Abuse in the Dementia Care Environment* (London: Alzheimer's Society).

³⁷⁴ See, for example, the YouGov survey carried out in December 2008 where 17 per cent of carers said they 'sometimes' felt threatened by the person for whom they were caring and two per cent said they 'often' felt threatened: YouGov (2009) *Alzheimer's – You Gov/ Channel 4 survey results* (London: YouGov/Channel 4), available at: www.yougov.co.uk/extranets/yougovarchives/content/pdf/C4%20results%20alzheimers.pdf.

³⁷⁵ Hirsch RD and Vollhardt BR (2008) Elder maltreatment, in *Oxford Textbook of Old Age Psychiatry*, Jacoby R, Oppenheimer C, Dening T and Thomas A (Editors) (Oxford: Oxford University Press), pp731–45, table 39.3.

with dementia as a 'vulnerable adult'.³⁷⁶ While a careful assessment may sometimes lead to the conclusion that the only way to protect the person's interests is by removing them from their current home, this outcome should never be assumed in advance. The autonomy and well-being interests of the person with dementia may be highly complex, and any benefits associated from a long-standing relationship must be weighed in the balance along with the nature and extent of the harm. Where it seems clear that the person with dementia does obtain benefit from their relationship with the person involved, then the focus should be on supporting the family or household as a whole with the aim of improving their knowledge of dementia and easing their burden of care, which may be what led them to lose control. We suggest that our recommendation in Chapter 3 (see paragraph 3.12) that professionals should treat carers as 'partners in care' will be of much positive benefit in avoiding and minimising harmful behaviour, by ensuring that carers feel appropriately supported and able to ask for help *before* a crisis is reached.

- 6.45 While some abuse will undoubtedly be of a malicious and criminal nature, there is considerable evidence as to the role played by ignorance, stress, ill-health and exhaustion on the part of carers. Allegations or evidence of abuse must always be thoroughly investigated and action taken to protect the person with dementia. At the same time it must be recognised that abuse and neglect may be the result of unmanageable pressure on the carer. **Our focus on solidarity emphasises the need both to act to protect the person with dementia and to support their carer where the person with dementia continues to benefit from their care. We suggest that these concerns add further weight to the importance of providing appropriate information, advice and peer support services to all those caring for people with dementia, as highlighted in Chapters 3, 6 and 7 (see paragraphs 3.25–3.29, 6.3 and 7.18).**

³⁷⁶ See, for example, the 'No Secrets' guidance in England: Department of Health and Home Office (2000) *No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse* (London: Department of Health), available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008486.