Dementia: ethical issues

a guide to the report

NUFFIELD
COUNCIL ON
BIOETHICS

In October 2009, the Nuffield Council on Bioethics published a report, *Dementia: ethical issues*, which considers the ethical issues that arise in the context of dementia.

Ethical difficulties arising in dementia include:

- deciding when and how to communicate a diagnosis;
- balancing a person's safety with their need for independence and freedom;
- deciding what is in the best interests of the person with dementia, for example when making decisions about their care and treatment;
- recognising that the needs of the person with dementia may sometimes conflict with the needs of others, especially carers;
- tackling discrimination against people with dementia;
- allocating resources to support people with dementia; and
- deciding what priority to give to dementia research.

The report was produced by an expert Working Party. To inform its deliberations, the Working Party consulted a wide range of people, including those with direct experience of living with dementia, people working in the field of dementia, and other members of the public. This guide sets out some of the conclusions and recommendations that are discussed in more detail in the report.

Notes in square brackets throughout refer to the chapters and paragraphs in the report.

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What is dementia?

A person with dementia will usually experience a progressive decline in their mental abilities because of damage to the brain. This damage may have many causes, including Alzheimer's disease, vascular dementia and Lewy body dementia.

The signs and symptoms of dementia include memory and communication problems, difficulties in daily living, changes in mood and behaviour, and the gradual loss of control of physical functions. However, we are beginning to understand how much people with dementia can still do and experience, despite the effects of their illness.

About 700,000 people in the UK currently have dementia and this is likely to increase to 1.7 million by 2051. Older people are more likely to develop dementia – one in five of us by the age of 85. However, some younger people develop dementia too. Dementia costs the UK over £17 billion a year.

Even with the best support, a person with dementia will usually experience significant changes in their life as a result of their declining mental abilities. These may lead to ethical problems for the individual with dementia, for family and friends who provide unpaid care and support (described as 'carers' in the report), for those providing paid care (care workers and professionals such as doctors), and for society as a whole.

There are no easy answers to these problems, but the aim of this report is to suggest ways of approaching them.

An ethical framework

The report sets out a 6–part ‘ethical framework’ to help those who face dilemmas in connection with the day-to-day care of someone with dementia. This framework also provides the basis for the recommendations to policy-makers we make throughout the report. As with any framework, it will need to be applied flexibly, and with compassion. There will rarely be one ‘right’ answer to any particular ethical difficulty [para 2.4 and box 2.1].

Component 1: A ‘case-based’ approach to ethical decisions

Ethical decisions can be approached in a three stage process:

- identify the facts that are relevant to the specific case;
- interpret and apply appropriate ethical values to those facts; and
- compare the situation with other similar situations to find ethically relevant similarities or differences.

Component 2: A belief about the nature of dementia

Dementia arises as a result of a brain disorder, and is harmful to the individual.

Component 3: A belief about quality of life with dementia

With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

Component 4: Promoting the interests both of the person with dementia and of those who care for them

It is generally accepted that autonomy and well-being are important aspects of our lives. This is just as true for people with dementia. **Autonomy** is often defined as the freedom to make your own choices, but people rarely make decisions in isolation. Autonomy can be promoted in people with dementia by encouraging relationships that are important to the person, and by supporting the person in maintaining their sense of self and expressing their values. A person's **well-being** includes both their moment-to-moment experience of pleasure, and more objective factors such as their level of mental ability.

The separate interests of carers must be recognised and promoted.

Component 5: Acting in accordance with solidarity

We are all dependent to some extent on one another (a concept often referred to as 'solidarity') and people with dementia are fellow citizens. We therefore have a responsibility to support people with dementia, both within families and in society as a whole.

Component 6: Recognising personhood, identity and value

The person with dementia remains the same, equally valued person throughout the course of their illness, regardless of the extent of the changes in their mental abilities and other functions.

Support for all those providing care

One of the key messages in the report is that those supporting and caring for people with dementia need much more support in tackling the ethical problems they meet every day. Guidelines are helpful, but not enough.

We conclude …

Professionals and care workers providing care to people with dementia should have access to ongoing education to help them respond to ethical problems. Carers (family and friends who provide unpaid care and support) who wish to access such education should be able to do so.

Professionals, care workers and carers should all have access to forums where they can share and receive support in making ethical decisions [paras 2.11–2.12].

What is an ethical approach to care?

Good, ethical care recognises the value of the person with dementia. It aims to promote their well-being and autonomy. At the same time, it pays attention to the interests of carers who provide so much of the day-to-day support.

We conclude…

How things are done, so that people with dementia feel that they are valued individuals, will often be far more important than the particular structure or format of services [para 3.5].

Professionals and care workers should treat families as 'partners in care', reflecting the solidarity being shown within the family [para 3.12].

Diagnosis

Early diagnosis has important benefits, but not every person with dementia will find that these advantages outweigh the possible disadvantages. A timely diagnosis is one which is at the right time for the person concerned, and for their family.

We conclude…

People should have access to good quality assessment and support from the time they, or their families, become concerned about symptoms that relate to a possible diagnosis of dementia. Doctors giving a diagnosis of dementia should actively encourage the person with dementia to share information with their family [paras 3.18–3.24].

There is some evidence to suggest that people in some cultural groups may be more hesitant in coming forward for diagnosis than those from other cultural groups, possibly because of stigma (see also page 6).

We conclude…

Further research should be carried out on the reasons why there is variation between cultures in readiness to come forward for diagnosis, and the role that misinformation and misunderstanding plays in these reasons [para 3.19].

Information and ongoing support

Access to supportive care, including appropriate information, emotional support and practical support, is essential for people to live well with dementia. Such care must be flexible, recognising the different needs, preferences and values of different individuals.

We conclude…

We welcome the idea of ‘dementia care advisers’, whose role would be to help people diagnosed with dementia to access appropriate services and support [para 3.27].

End of life care

End of life care for people with dementia is a matter of particular concern. At the moment, people with dementia are less likely than others to receive good quality palliative care.

We conclude…

We welcome the recent emphasis throughout the UK on the importance of improving end of life care for people with dementia. A key factor will be the development of models of end of life care which are appropriate to dementia. We welcome the commitment in the English dementia strategy to develop and evaluate such models [para 3.45].

Image: DSDC

Dementia and society

Stigma is still very common in dementia. As a result, people with dementia may feel devalued and excluded from mainstream society. Our ethical framework (pages 2–3), emphasises the equal value of people with dementia and the importance of acting in solidarity with those affected by dementia. There is therefore a clear moral imperative to tackle this stigma.

Combating stigma and promoting inclusion

We endorse the plans in England, Wales and Scotland to improve public awareness of dementia. However, information campaigns are only one part of the story. For dementia to be truly ‘normalised’, it needs to become an accepted, visible part of our society, in the same way that physical disability is increasingly recognised as ‘normal’. People with dementia need to feel comfortable carrying on with their usual activities, such as going to a club or out to lunch, participating in church activities, or taking part in voluntary work.

“Service providers” such as shops, leisure facilities and restaurants have a legal duty under the Disability Discrimination Act to make “reasonable adjustments” to enable people with dementia to use their services. Often, however, they may not realise this. Even if they do, they are unlikely to have sufficient knowledge of dementia to make appropriate adjustments.

We conclude…

The Equality and Human Rights Commission should take appropriate action to publicise:

- the legal duties to which all “service providers” are subject under the Disability Discrimination Act to ensure equal access to their services by people with dementia; and
- ways in which this could be achieved.

The Disability Discrimination Act 1995 Code of Practice should explicitly address dementia with examples of good practice [para 4.31].

The role of society in providing care and support

People with dementia experience a number of disadvantages in the current care system. The services needed by people with dementia are often classed as 'social' services. However, these services are sometimes not available until a crisis occurs, because of financial pressures on social services departments.

Dementia is a medical disorder. The needs arising out of the disorder should therefore be met in the same way as those arising out of other serious long-term illnesses such as cancer. It is not acceptable to make people with cancer wait until their support needs have reached a crisis before providing that support. It should not be regarded as acceptable for people with dementia to wait in this way.

We conclude…

The availability of services needed by people with dementia should not be determined by classifications of care. In allocating resources, and in determining standards of care, it should make no difference whether the care is classified as 'health' or 'social' [para 4.41].

Image: DSDC

Making decisions

People have the legal right to make their own decisions about things such as what medical treatment to accept or where to live, as long as they are capable of doing so. This applies to people with dementia too. As dementia progresses, however, it can get harder for people to make their own decisions.

What is the law?

The Mental Capacity Act 2005 (covering England and Wales) and the Adults with Incapacity (Scotland) Act 2000 set out how a decision can be made if a person is not able to make a particular decision for themselves. A similar Act has been promised for Northern Ireland. Detailed Codes of Practice provide extra information on how the Acts should work in practice.

The law says that it must always be assumed that someone can make their own decisions, until it is shown that they can't. Where decisions are made for people who lack capacity, such decisions must be in the person's 'best interests' (England, Wales and Northern Ireland) or have the potential to 'benefit' the person (Scotland).

In general, these Acts have been welcomed by those working in the field of dementia. There are a number of areas, however, where extra guidance on how the Acts should work in practice would be helpful.

Support for making decisions

People with dementia should be supported to help them take part in decisions as much as possible. If they can't make a decision entirely on their own, then they may still be able to make decisions jointly with trusted family or friends.

We conclude…

The Codes of Practice made under the Mental Capacity Act and the Adults with Incapacity (Scotland) Act should emphasise the importance of good communication and supportive relationships with families, so that joint decision making is encouraged wherever appropriate [para 5.23].

Working out 'best interests' or 'benefit'

When deciding on the right thing to do, both the past wishes and feelings of the person and their wishes and feelings *now* must be taken into account. However, sometimes past and present wishes may be quite different.

We conclude…

Both past and present wishes are an expression of a person's autonomy.

Extra guidance should be provided in the mental capacity Codes of Practice on how past and present wishes and preferences should be taken into account where these appear to conflict. This guidance should emphasise that neither past nor present can automatically take precedence. The relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider [para 5.32].

Image: DSDC

Advance decisions and advance care planning

People who can still make their own decisions sometimes write 'advance decisions' (also called 'advance directives' or 'living wills') to say what kind of care or treatment they want in the future when they are no longer able to decide for themselves. Advance decisions to *refuse* treatment are legally binding, as long as they have been properly made.

Some people see advance decisions as a good way of making sure their wishes are followed in the future. Others believe that we can never 'second-guess' what we will want in the future, and that an advance decision may lead to bad care.

In end of life care, the term 'advance care planning' is used for a much broader approach to planning for the future. As well as the kind of medical treatment the person would want, or not want, an advance care plan may include their wishes about where they would like to be as they are dying, their particular likes and dislikes, and who they would most want to be with them.

We conclude…

It is right for the law to allow people to make an advance decision to refuse treatment if they wish to do so. However, an advance refusal of treatment may not always work in the way the person expected. We therefore welcome recent NHS guidance that provides a model advance refusal form and suggests a number of helpful safeguards.

Where individuals wish to make decisions about their future care, we suggest this is best achieved in the broader context of advance care planning. Such planning should begin early and be regularly reviewed [paras 5.40, 5.41 and 5.48].

Proxy decision-making: welfare attorneys

People who are still able to make their own decisions may choose someone they trust to make decisions for them in the future. The person chosen is known as a 'welfare attorney'. The welfare attorney must always act in the best interests of the person with dementia when making decisions.

Welfare attorneys have many advantages over advance decisions, as they have up-to-date information about the decision to be made. However, there are concerns that some people may find it too expensive or complicated to nominate a welfare attorney.

We conclude…

In principle, the process of appointing a welfare attorney should be free of charge for everyone, as they represent a 'social good'. At the least, people with dementia should have support in nominating a welfare attorney if they wish to do so [paras 5.55–5.57].

There will be times when doctors disagree with the welfare attorney over the best interests of the person with dementia. Such disputes can be referred to court. However, there is little guidance for doctors as to what level of concern should trigger this process.

We conclude…

More guidance is needed about when it is appropriate for professionals to challenge the decision of a welfare attorney in court. Significant weight should be placed on the fact that the welfare attorney was previously chosen and trusted by the person about whom the decision is being made [para 5.63].

Dilemmas in care

Ethical dilemmas arise on a daily basis for those providing care for people with dementia. The way in which these dilemmas are approached will have significant impact on the lives of people with dementia and their carers. This is why support in dealing with ethical issues is crucial. We hope that the ethical framework presented on pages 2–3 of this guide will help in approaching these dilemmas. We discuss several specific dilemmas below.

Assistive technologies

New technologies have the potential to make a big difference to the lives of people with dementia and their carers. For example, 'smart' houses, with taps or cookers that turn off automatically, may make it possible for people to live in their homes for longer. Tracking devices may make it safer for people to go out on their own. However, some people are concerned that this kind of monitoring intrudes too much on people's privacy.

We conclude…

Where a person with dementia is not able 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, for example about privacy;
- the actual benefit that is likely to be achieved;
- the extent to which carers' interests may be affected; and
- the dangers of loss of human contact [para 6.12].

Balancing freedom and risk

Taking risks is part of everyday life – a life without risk would be unimaginable. When caring for someone else, there is a natural desire to try to reduce risk as much as possible. However, this may mean missing out on benefits and restricting a person's freedom.

For example, it may seem safer not to allow a person with dementia to use the cooker. However, if they gain pleasure and a sense of achievement from cooking, the benefits may outweigh the risks.

'Risk assessments' often focus only on the possible risks, without considering what opportunities and benefits are being lost as a result.

We conclude…

'Risk assessments' should be replaced by 'risk-benefit assessments'. These should 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 [para 6.17].

Image: DSDC

Restraint

It may be legal for a person to be restrained if this would prevent harm either to the person or others. 'Restraint' may be physical or less obvious, such as leaving a person in a low seat that they cannot get out of without help. Being restrained can be very distressing and demeaning. However, carers may sometimes find that a lack of outside help leaves them little choice but to restrain the person for whom they care, in order to get on with essential household tasks.

The Mental Capacity Act limits the use of restraint to circumstances where it is a "proportionate" response to the likelihood of the person suffering harm. There is, however, little guidance on what counts as a "proportionate" justification for restraint.

We conclude…

There should be:

- more guidance for carers on when restraint might count as "proportionate";
- support for carers that will minimise the need for restraint at home; and
- detailed and practical guidance on the appropriate use of restraint in care homes for all those working in this sector [para 6.38].

The needs of carers

There will often be a very close relationship between the person with dementia and their carers. Their needs and interests become intertwined. Caring for people with dementia must therefore also involve caring for the carers.

Joint support for the person with dementia and their carers

A diagnosis of dementia has serious implications for those close to the person receiving the diagnosis. Close family and friends have to adjust to the effects it will have on their own lives.

We conclude…

Professional support (from doctors, nurses and others) in dementia should have a wide focus that includes helping the family to support the person with dementia [para 7.19].

The need to be trusted

The issue of trust is central in any caring relationship. Most carers provide a level of care that compromises their own health and well-being, and want to help and support the person with dementia as much as they are able.

We conclude…

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’ [para 7.23].

Confidentiality

Doctors, nurses and other professionals may be hesitant about sharing confidential information with carers if the person with dementia is not able to give consent. The current legal position is 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 conclude…

We support the current legal position on confidentiality. However, 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, and carers do not always get the information they need to carry out their caring role. In general, carers who are involved in making a decision on behalf of a person with dementia will need the same level of information as any other member of the care team [para 7.26].

Considering carers' own interests

The interests of the person with dementia and their carers are often complex and intertwined. In a family, it will rarely be the case that one person's interests always take priority: some thought will be given to everyone's interests, and some degree of compromise found.

We conclude…

Professionals such as doctors, nurses, clinical psychologists and social workers have an important role to play in supporting carers to think about their *own* needs when weighing up difficult decisions, particularly around future care options [para 7.37].

Image: DSDC

Research

The amount of funding available for dementia research appears low, given both the number of people with dementia and the effect dementia has on people's lives.

Funding

Research funding bodies rightly choose to fund research that is important and high quality. However, these criteria alone are not enough to make sure that there is a fair distribution of research funding between the needs of very different parts of the population.

We conclude…

The major research funders should:

- explain more clearly how and why they divide their research funds between areas of research that have the capacity to benefit very different groups of the population;
- if necessary, take active steps to support and encourage researchers who are capable of carrying out high-quality research in dementia; and
- encourage more research into the experience of living with dementia and how people with dementia can be supported to live the best possible lives [paras 8.17– 8.18].

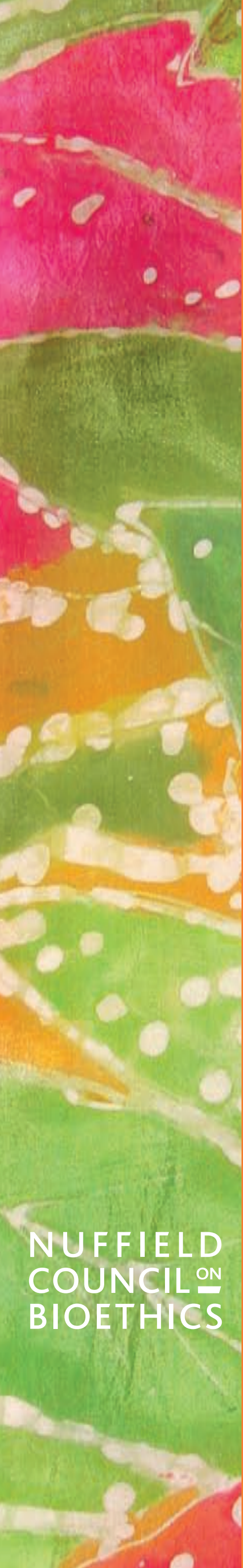
Who should be involved in research?

People with dementia who understand what is involved in a particular research project decide for themselves whether or not to take part. Those who cannot decide for themselves may be able to take part as long as a number of legal requirements are met.

We conclude…

Current legal safeguards are an appropriate way of protecting people with dementia from harm. However, more should be done to make it easier for those who have expressed a wish to take part in research to do so. For example:

- Clinical trial networks, which bring together doctors and people with dementia who want to take part in research, should be encouraged.
- The possibility of giving welfare attorneys the power to decide if a person with dementia should take part in research should be considered. At present, this is possible in Scotland but not in England or Wales.
- There should be research into how advance decisions could be used to help make future decisions about research participation.
- Information about a research project should be adapted so that it is easier for people with dementia to understand the key issues and give consent for themselves [paras 8.44–8.45].



Summary

Those supporting and caring for people with dementia need much more support in tackling the ethical problems they meet every day. Guidelines are helpful, but not enough.

A 6–part 'ethical framework' aims to help those who face dilemmas in the day-to-day care of someone with dementia.

Recommendations are made in the following areas:

- diagnosis, access to health and social care, and end-of-life care for people with dementia;
- stigma and including people with dementia in society;
- making decisions about care and treatment;
- dilemmas in day-to-day care, such as using restraint, using assistive technologies, and balancing risk and freedom;
- recognising the needs of carers; and
- research priorities and participation.

Copies of the report and this guide are available
to download from the Council's website:
www.nuffieldbioethics.org

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'*Explosion of colour*' by Gwen Finney
This painting on silk was produced during a series of workshops for people with dementia at Hillcrest Day Hospital, Smethwick, West Midlands funded by the charity Sandwell Third Age Arts which provides creative activities for older people with mental health problems and dementia. www.staa.org.uk

Photos:
The photos marked 'DSDC' throughout this guide were provided by the Dementia Services Development Centre at the University of Stirling, and taken by Tony Marsh
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