

# Dementia: ethical issues

Consultation paper –  
shortened version

NUFFIELD  
COUNCIL ON  
BIOETHICS

This is a shortened version of the Nuffield Council on Bioethics consultation paper *Dementia: ethical issues*. It is aimed at people who prefer a briefer document, which may include people with dementia. The full version and this document can be downloaded from the Council's website: [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org). Please contact the Council for printed copies, including large print versions:

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London WC1B 3JS  
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### Where to send your comments

There are a number of different ways in which you can send us your comments:

- in writing to Nuffield Council on Bioethics, 28 Bedford Square, London WC1B 3JS
- by email to [consultation@nuffieldbioethics.org](mailto:consultation@nuffieldbioethics.org)
- by recording your comments on a tape and sending the tape to us at:  
28 Bedford Square, London WC1B 3JS.

Please include the 'Consultation reply form' at the end of this document so that we know how you want us to use your comments.

**Closing date for responses: 31st July 2008**

Thank you

# Introduction

The Nuffield Council on Bioethics is an independent organisation that looks at ethical issues in biology and medicine. It is currently considering ethical dilemmas that are faced by people with dementia and those who care for them. The sort of issues the Council is interested in include:

- How people with dementia are involved in making decisions about their treatment and care
- Whether it is right to include people with dementia in research, if they are no longer able to choose for themselves
- How people with more advanced dementia are treated by those caring for them and how much control they have over their own lives
- What difficulties family and friends experience when caring for a loved one with dementia.

The Council is very interested in learning about the opinions of people with dementia and others affected by dementia. It will consider these opinions very carefully when writing its Report. We expect to publish the Report in the autumn of 2009.

## How to respond

The following pages set out the questions we would like to ask, along with a little background information. **Please feel free to answer as many or as few questions as you wish. You may prefer just to look at one or two sections which particularly interest you.** The six sections are:

1. The experience of dementia (page 2)
2. How society sees dementia (page 4)
3. Making decisions (page 6)
4. Dilemmas in care (page 8)
5. Carers (page 10)
6. Research (page 11)

You can send us your comments in writing, on tape or by email. Our postal address and email address are listed on the opposite page. If you would like a list of the questions with space to write your answers, please just phone us on 020 7681 9619 or email us at [consultation@nuffieldbioethics.org](mailto:consultation@nuffieldbioethics.org).

Please send us your comments by **31st July 2008**. Please also fill in the 'Consultation reply form' at the end of this leaflet, so that we know how you want us to use your comments.

# The experience of dementia

## The impact of 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, Lewy body dementia and vascular dementia. Symptoms of dementia include problems with memory and communication, disorientation, difficulties with activities of daily living, and behaviour that seems out of character. As yet, there are no drugs that can stop or cure dementia, although some drugs may help slow down the progress of the dementia for a while.

The impact of dementia may be very different for different people. People's experiences of dementia are shaped by factors such as their earlier lives, their family and social circle, their beliefs and values, and the care and support available.

### Q1

In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most?

### Q2

What difference (if any) does a person's religion, culture or family background make?

## Diagnosis

Early diagnosis of dementia may be very helpful. It can give people with dementia and their families plenty of time to access advice, information, care and support. Early diagnosis may also enable people with dementia to plan their future.

One disadvantage of very early diagnosis is that it may be wrong. People may be given a diagnosis of dementia when in fact they are only experiencing memory problems which may never develop into dementia. In the future it may become possible to use techniques such as blood tests to diagnose dementia even before the person experiences any symptoms.

### Q3

When do you think a diagnosis of dementia should be made?



## Person-centred care

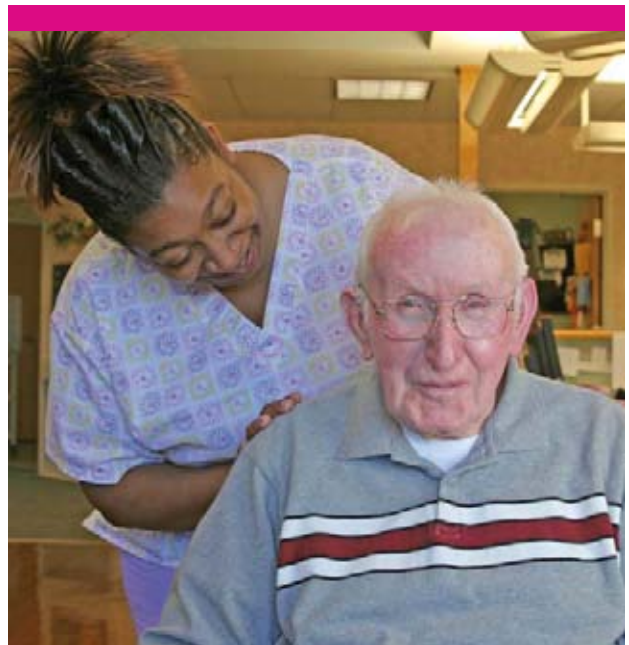
Over the years, people have become aware that there is more to dementia than simply a disease of the brain. For example, many of the 'symptoms' associated with dementia, such as mood changes or aggressive behaviour, may not be a direct result of the dementia itself. Instead, they may be the person's way of expressing pain or distress when other forms of communication have become impossible. Similarly, as recent memories get lost, a person with more advanced dementia may imagine themselves in situations from many years ago, and act accordingly. For example, a mother may try to look after her children, even though they are long grown-up.

The idea of *person-centred care* is based on the idea that a person's experience of dementia will be strongly affected by their earlier experiences in life. It starts from the belief that the person is still 'there', however severe the dementia. It is therefore important for those caring for people with dementia to look 'beyond' the dementia and see the real person.

Many people think the idea of person-centred care is very important when trying to improve the quality of life of people with dementia. Others think that the expression has been used so much that it is meaningless: all care now seems to be described as person-centred.

### Q4

Is the idea of person-centred care helpful? If so, in what way?



## Personal identity

Everyone changes during their lifetime, as they have new experiences and form new relationships. One of the most common fears in connection with dementia is that it might change a person more profoundly. Many family and friends will continue to recognise typical personal characteristics of their loved one with dementia, despite changes in mood and behaviour. However, others may say that the person with dementia has changed out of all recognition. For example, a wife might say: "That's not the man I married. He isn't like that."

### Q5

Do you think that dementia can change people so much that they actually stop being 'themselves'?

# How society sees dementia

## Stigma

For some people, dementia has very negative associations, especially in its later stages. People with dementia may fear that their diagnosis of dementia will lead to family, friends, health professionals and even society as a whole treating them differently. They may feel excluded from ordinary life and the sorts of activities they used to enjoy.

### Q6

In your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?

### Q7

Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?



## The government's duty to support people with dementia

There are many different opinions about what the government should do to support people with dementia.

- Some people believe that the government should provide all the necessary services.
- Some believe that the government should cover all or most of the cost of care, but that other organisations (such as private care homes or voluntary organisations) should provide the actual services. It would then be up to families, perhaps helped by social workers, to make their own arrangements for care.
- Yet others believe that individuals and their families should provide for their own needs wherever possible, with the government only providing back-up if necessary.

### Q8

What duties do you think the government owes towards people with dementia and their families, and why?



# Making decisions

## The law on making decisions

People have the legal right to make their own decisions about things like what medical treatment to accept or where to live, as long as they are capable of doing so. Sadly, it can get harder and harder for people to make their own decisions as dementia progresses, even with help. The law in England, Wales and Northern Ireland says that if people are not able to make a particular decision for themselves, then others must do what is in their 'best interests'. The law in Scotland is very similar: it says that actions should be taken that 'benefit' people who cannot decide for themselves.

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. This may be difficult if these wishes and feelings seem to have changed. For example, a person might have taken great pride in her appearance in the past, while now she always resists getting dressed and wants to go outside in her dressing gown. Her family or other carers will have to decide how much fuss to make about what she wears.

### Q9

How do you think a person's *past* wishes and feelings should be balanced with their *current* wishes and feelings, if these seem quite different? Is the past or the present more important?

It is not always easy for families or for professionals to be sure whether or not someone is capable of making a particular decision. There will be 'grey areas' where it is very hard to tell. For example, a person might seem to be able to make their own decisions without help, but the decisions they make might seem very out of character, such as spending money much more freely than they used to do.

Some people think that the person should be left alone to do what they want, unless what they want is clearly very harmful. Other people think that family or friends or professionals ought to intervene in case the person makes unwise decisions they might later regret.

### Q10

What do you think family or friends should do if they are worried about the decisions a person with dementia is making?





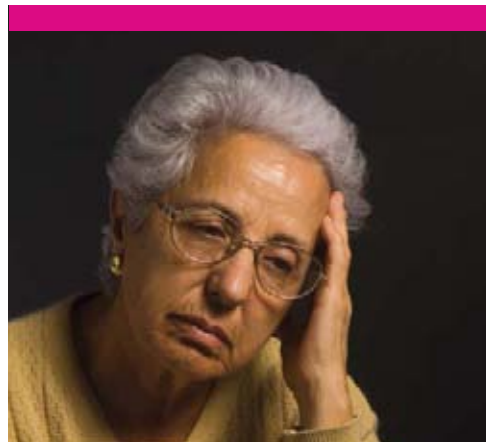
## Advance directives

People who can still make their own decisions sometimes write 'advance directives' (also called 'advance statements', 'advance decisions' or 'living wills') to specify what kind of care or treatment they want in the future when they are no longer able to decide for themselves. Some people may say in their advance directive that they do *not* want a particular kind of medical treatment. Doctors are then not allowed to give that treatment. Some people may use an advance directive to say what care or treatment they *would* like in the future. Doctors are not obliged to provide that treatment if they think it is not right for the person. However, the information provided in the advance directive may be very helpful for family or doctors if they have to decide what treatment is in the 'best interests' of the person with dementia.

Some people think advance directives are a very good way for people with a diagnosis of dementia to say early on how they would like to be treated later. Other people think that it is never possible to guess how we are likely to feel in the future when our lives may be very different. They think that it would be wrong to follow an advance directive if the person who wrote it now seems to have different feelings from before.

### Q11

Should people be encouraged to write advance directives? How should they be used?



## Welfare attorneys

People who are still able to make their own decisions may also choose someone they trust (such as their husband or daughter) 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.

However, people don't always agree about what is in a person's 'best interests'. For example, people have different opinions about when it is right to give drugs to calm down a distressed or angry person. So it is possible that a welfare attorney might not always agree with the doctor about what is right for the person with dementia.

### Q12

What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

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# Dilemmas in care

People with dementia tend to find it harder to communicate with others as their disease progresses. They may feel increasingly confused and disoriented, and as a result may sometimes feel frustrated or frightened. Those caring for them may sometimes find it difficult to know how best to respond to them or reassure them. The Nuffield Council on Bioethics would like to know what you think about some of the difficult ethical dilemmas that can arise in these circumstances.

## Truth-telling

We normally expect other people to tell us the truth, even if the truth is distressing. Some people argue that this is particularly important when caring for someone with dementia: if someone cannot trust their own memory or judgment, it is all the more important for them to be able to trust others. If lying to a person with dementia is seen as acceptable, then family and professional carers may start routinely telling them lies, just because it is easier.

Other people argue that there are times when it is appropriate to tell a lie, for example in order to reassure a person with dementia, encourage them to do something, or avoid causing them distress.

### Q13

Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

## Freedom of action

Everyone accepts some degree of risk in their everyday lives: for example when cooking, crossing the road or driving a car. There is a natural desire for carers (family, friends and professionals) to try to reduce risks as far as possible for the people they look after. On the one hand, it seems right to protect others from avoidable risks, particularly when they cannot weigh up the risks clearly themselves.

On the other hand, trying to remove *all* hazards of daily life may affect the quality of that life. For example, a person who has always loved cooking may find it very distressing if she is not allowed in the kitchen because of concerns about sharp knives or the hot stove. Similarly, people may find it distressing if they are not allowed privacy in the bathroom because of concerns about falling.

### Q14

Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?

## Restraint

It is legal for a person to be restrained in order to prevent harm either to the person or to others. Restraint may be physical (such as using force to move someone from one place to another) or it may be less obvious. For example, placing someone in a low seat that he or she cannot leave without help or giving an agitated person calming drugs are both forms of restraint. Being restrained may be a very distressing and demeaning experience.

Caregivers may feel that they have no choice about using restraint in some circumstances, for example in order to prevent someone being injured. Some people, though, believe that restraint is used too often on people with dementia, and that it should be possible to avoid many difficult situations arising in the first place. For example, if a person with dementia is behaving in an aggressive way, it may be possible to find out what is 'triggering' that behaviour and then take action to avoid those triggers in the future. However, this may involve a lot of staff time.

### Q15

Should any forms of restraint be allowed? If so, when?

## New technologies

New technologies have the potential to make a big difference to the lives of people with dementia and their families. For example 'smart' houses, with taps or cookers that turn off automatically, may make it possible for people to live in their own homes for much longer. 'Tagging' devices may make it possible for people to go out much more on their own: the device will enable someone to find them quickly if they forget the way home. Many of these technologies involve some kind of monitoring such as sensors in the home. Some people are concerned that this kind of monitoring intrudes too much on people's privacy.

### Q16

Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?



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## Carers

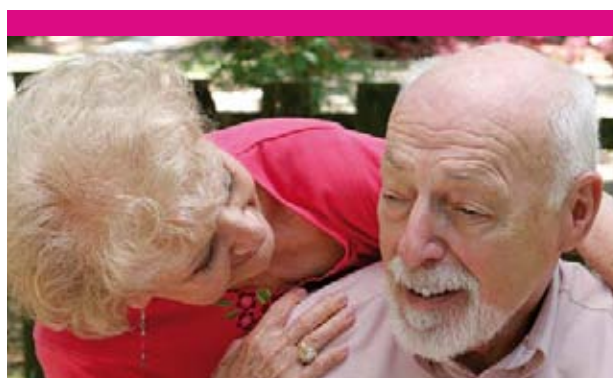
### The impact of being a carer

People with dementia are very often cared for by one or more family members. Whilst many people willingly accept becoming a 'carer', their new role will still have a major effect on their lives. Most carers of people with dementia are themselves over retirement age and may have significant health problems of their own.

As a person's dementia progresses, they will find it harder to make their own decisions. Eventually, the carer will probably have to decide many things for them. It can be very difficult for a carer to decide what is right for the person with dementia and at the same time think about their *own* needs. Sometimes, the needs of the carer and the needs of the person being cared for may be very different. For example, a person with more advanced dementia may find it very comforting to have her husband close by all the time, but the husband may need a bit of time to himself.

#### Q17

How can professionals (such as doctors and social workers) help if a carer's own needs are very different from the needs of the person for whom they care?



### Confidentiality

Everyone has the right to have their personal information, such as their health records, kept confidential. People with dementia are entitled to choose whether or not they want to share confidential information, as long as they understand enough to make this decision.

If people are no longer able to decide whether or not they want to share information about themselves, then doctors and other health professionals have to decide whether it is right to share information with family carers. Some people think that it is too difficult for family carers to get the information they need in order to make decisions for their loved one. Other people think that health professionals share too much information.

#### Q18

Is it too difficult for family carers to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?

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# Research

## Research priorities

Research into dementia has a number of different aims. Research can try to improve our understanding of the processes in the brain that lead to dementia. It can try to find treatments that slow down, stop, or even reverse the damage that causes dementia. It can try to find better ways of caring for people with dementia so that they have a better quality of life.

Some research may help people with dementia straight away, such as research into ways of caring. Other kinds of research may be more likely to benefit future generations, such as research trying to improve scientists' understanding of the brain.

### Q19

What should research into dementia be trying to achieve? On what basis should funding be allocated?



## Involvement in research

People with dementia who understand what is involved in a particular research project will decide for themselves whether or not they want to take part. However, sometimes it may be suggested that people with advanced dementia who are not able to decide for themselves should be involved in research. Perhaps there is a chance that the person might benefit from the research, for example by taking an experimental drug. Or perhaps the person is not likely to benefit directly himself or herself, but the risks or discomfort of the research are very low, and the information gained might help other people with dementia in the future.

Some people feel that people who cannot make their own decisions should *never* be involved in research that is not likely to benefit them. Some feel that people who cannot decide for themselves should only be involved in research if they have made very clear in the past that they would like to do so. Others feel that it is acceptable to involve people who cannot decide for themselves in research, as long as consent has been given by someone very close to the person such as a husband or wife.

### Q20

What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?

## Other issues

### Q21

Are there any other ethical issues relating to dementia that we should consider?



## Consultation reply form

Please provide us with a little information about yourself, so that we can send you a copy of the final Report when it is published and invite you to the launch event. We also need to know if you are happy for us to publish your response or quote your comments in the Report. We will only do this if you give us permission.

Name

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Address

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Email

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Our final Report lists the names of people who have given us their comments.  
Can we include your name in this list?

- Yes, I am happy for my name to be included in the list
- No, I do not want my name to appear in the list

May we quote your comments in our Report?

- Yes and you can give my name
- Yes, but anonymously
- No, please don't quote me

When we publish our Report, we also publish responses to our consultation on our website.  
May we publish your response?

- Yes and you can give my name
- Yes, but anonymously
- No, please don't publish my response

Why are you interested in dementia and dementia care?

- Personal diagnosis of dementia
- Family/carer of someone with dementia
- My work is connected with dementia
- Other .....

We will only keep this information until we publish our Report.

Large print versions of the consultation paper can be obtained from the Nuffield Council on Bioethics using the following contact details:

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