



Dementia:
ethical issues
Consultation paper

NUFFIELD
COUNCIL ON
BIOETHICS

Responding to the consultation

It would be most helpful if you could send responses to us electronically. Responses can be submitted online via our dedicated consultation website: <https://consultation.nuffieldbioethics.org>. Alternatively, you can email your response together with the respondent's form opposite (electronic document available at www.nuffieldbioethics.org) to: consultation@nuffieldbioethics.org. **If we receive your response electronically, there is no need for you also to send a paper copy. You will receive an acknowledgement of your response. If you would prefer to respond by post or by fax, you may send your completed response and respondent's form (opposite) to:**

Katharine Wright
Nuffield Council on Bioethics
28 Bedford Square
London WC1B 3JS
UK

Fax: +44 (0)20 7637 1712
Telephone +44 (0)20 7681 9619

A shortened version of this consultation paper is also available for people who would prefer a briefer document, which may include those with dementia. Both documents can be downloaded from the Council's website: www.nuffieldbioethics.org. For printed copies, please contact the Council at the above address.

Thank you.

Closing date for responses: 31st July 2008

For information about obtaining a large print version of the consultation paper please contact the Council using the above details.

Cover image

'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.

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Dementia: ethical issues

Respondent's form

Please complete and return with your response by **31st July 2008**

Your details

Name: _____

Organisation: (if applicable) _____

Address: _____

Email: _____

About your response

Are you responding personally (on your own behalf)
or on behalf of your organisation?

Personal / Organisation

May we include your name/your organisation's
name in the list of respondents that will be
published in the final report?

Yes

No, I/we would prefer
to be anonymous

If you have answered 'yes', please give your name or your organisation's name as it should appear
in print (this is the name that we will use for your response):

This response may be quoted in the report

Yes, attributed to myself
or my organisation

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Yes, anonymously

This response may be made available on the
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No

Yes, anonymously*

* If you select this option, please note that your response will be published in full (but excluding this form), and if you wish to be anonymous you should ensure that your name does not appear in the main text of your response. The Nuffield Council on Bioethics cannot take responsibility for anonymising responses in which the individual or organisation is identifiable from the content of their response.

Why are you interested in dementia and dementia care? (tick as many as apply)

- Personal diagnosis of dementia
- Family/carer of someone with a diagnosis of dementia (past or present)
- Connected with a charity or voluntary body concerned with dementia
- Working in healthcare (e.g. healthcare assistant, nurse, psychologist, doctor, NHS manager)
- Working in social care (e.g. careworker, care home manager, social worker)
- Working in other public services (e.g. housing)
- Legal interest
- Academic/research interest
- General interest/other

Please let us know where you heard about the consultation:

- Website of the Nuffield Council on Bioethics
- Sent copy by Nuffield Council on Bioethics
- Media article
- Email mailing list
- Other (please state): _____

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We ask for your address in order that we can send you a copy of the report when it is published and invite you to the launch event. We would also like to be able to contact you again about both this topic and future work by the Council that may be of interest to you. (Please note that we do not make your address available to anyone else and we do not include it with the list of respondents in the report.)

May we keep your contact details for these purposes?

Yes, you may keep my contact details

- only until the Report is published, so that you can send me a copy and invite me to the launch event
- until I notify you otherwise
- Please do not keep my contact details

Would you like to receive updates by email of the Council's activities (published three times each year)?

If so, please provide your email address below

Closing date for responses: 31st July 2008

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Professor Peter Harper
Professor Ray Hill FMedSci
Professor Søren Holm
Professor Tony Hope*
Mr Anatole Kaletsky
Dr Rhona Knight FRCGP
Professor Alison Murdoch
Dr Bronwyn Parry
Professor Hugh Perry MA DPhil FMedSci
Professor Nikolas Rose
Professor Jonathan Wolff

* Co-opted member of the Council while chairing this Working Party

Secretariat

Hugh Whittall	Catherine Joynson
Katharine Wright	Caroline Rogers
Harald Schmidt	Julia Trusler
Carol Perkins	Kate Harvey
Audrey Kelly-Gardner	

The terms of reference of the Council are:

- 1 to identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern;
- 2 to make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body;
- 3 in the light of the outcome of its work, to publish reports; and to make representations, as the Council may judge appropriate.



Working Party members

Professor Tony Hope (Chair)

Professor of Medical Ethics, University of Oxford, honorary consultant psychiatrist

Professor Janet Askham

Director of Research, Picker Institute

Mary Baker MBE

President, European Federation of Neurological Associations

Harry Cayton

Chief Executive of the Council for Healthcare Regulatory Excellence, former National Director for Patients and the Public at the Department of Health and former Chief Executive of the Alzheimer's Society

Chris Chaloner

Ethics Advisor, Royal College of Nursing

Dr Jim Eccles

Consultant Physician, the Leeds Teaching Hospitals NHS Trust

Dr Julian Hughes

Consultant in Old Age Psychiatry, Northumbria Healthcare NHS Foundation Trust

Dr Rhona Knight

General Practitioner; Member of the Council

Dr Gemma Jones

Educator/consultant on dementia care and design issues related to dementia care; Chair, Alzheimer Café UK

Dr John McMillan

Senior Lecturer in medical ethics, The Hull York Medical School

Professor Jill Peay

Professor of Law, London School of Economics

Professor Hugh Perry

Professor of Experimental Neuropathology, University of Southampton; Member of the Council

Professor Ruud Ter Meulen

Professor of Ethics in Medicine, University of Bristol

Dr David Wilkinson

Consultant in Old Age Psychiatry, Moorgreen and Western Community Hospitals, Southampton

Working Party Terms of Reference

In the light of the increasing prevalence of the various forms of dementia in the UK, and of developments in neuroscience which provide a better understanding of these conditions and of the care and treatment that can be provided, the Working Party will:

- 1 Identify and consider the ethical, legal, economic and social issues, including issues of social responsibility, that arise in the care and treatment of those with dementia arising from degeneration of the brain;
- 2 Examine ethical issues affecting individuals with dementia, carers, families, healthcare providers, social services and society, in particular those surrounding:
 - (a) decision making and capacity to consent;
 - (b) respect for the autonomy of both the individual and their family/carers;
 - (c) 'best interests' and 'quality of life' of both the individual and their family/carers;
 - (d) the implications of the changes that affect the behaviour of people with dementia.
3. Consider the legal, policy and educational implications of these ethical issues for the care and support of individuals with dementia and their families taking account of different cultural and social contexts, including:
 - (a) the implications of an 'advance directive' or 'living will' in relation to palliative care and end-of-life issues, produced before, or after diagnosis;
 - (b) the adequacy of care and support for individuals with dementia and their families.

Table of contents

List of questions	2
Introduction	6
Section 1: What is dementia and how is it experienced?	8
What is meant by dementia?	9
Medical and psychosocial aspects of dementia	9
Prevalence of dementia	9
The experience of dementia	10
Ethnic, cultural and social factors	11
Developments in scientific understandings of dementia	11
Diagnosis	12
Stigma and dementia	12
Section 2: Person-centred care and personal identity	14
Person-centred care	15
Personal identity	16
Section 3: Making decisions	18
Decision-making capacity	19
Best interests and benefit: the law	19
Best interests and benefit: dilemmas	20
Welfare attorneys: the law	21
Welfare attorneys: dilemmas	21
Advance directives: the law	22
Advance directives: dilemmas	22
Your general views about legislation governing mental incapacity	23
Section 4: Aspects of care and support	24
Ethical dilemmas in care	25
Truth-telling	25
Freedom of action and risk	26
Restraint	26
Education and training	27
New technologies	28
The duty to care for people with dementia	29
Section 5: The needs of carers	30
The impact of being a carer	31
Confidentiality	32
Section 6: Research	34
Research priorities	35
Involvement in research	35
Section 7: Other issues	38

List of questions

(please answer as many or as few as you please)

What is dementia and how is it experienced?

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 by people with dementia and those caring for them?

Q2

From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

Q3

From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

Q4

What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Q5

What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

Q6

Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

Q7

In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Q8

What part, if any, does stigma play in dementia care?

Q9

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

Person-centred care and personal identity

Q10

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

Q11

In your view, to what extent is it correct to say that dementia changes a person's identity?

Q12

What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

Making decisions

Q13

When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

Q14

What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

Q15

How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

Q16

What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

Q17

What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

Q18

What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

Aspects of care and support

Q19

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

Q20

In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

Q21

Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

Q22

Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

Q23

What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

Q24

What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

The needs of carers

Q25

How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

Q26

What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

Q27

In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a couple (or of a household), instead of concentrating solely on the interests and needs of the individual?

Q28

From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

Research

Q29

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

Q30

What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

Q31

Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research that you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

Other issues

Q32

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

Introduction

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biological and medical research. Established by the Nuffield Foundation in 1991, the Council is an independent body, funded jointly by the Foundation, the Medical Research Council and the Wellcome Trust. The Council considers a topic in depth and then publishes a report of its findings and makes recommendations to policy makers.

The Council has established a Working Party to examine the ethical issues raised by degenerative neurological diseases which result in dementia. This is a very important area both now and for the future. One in 20 people over 65 currently has a form of dementia and the UK's ageing population means that increasing numbers of people, their families, healthcare staff and carers are having to deal with the difficulties that dementia can cause. At the same time, developments in neuroscience are increasing our understanding of these conditions and helping us to provide better treatment and care. New diagnostic methods and therapies have been and are being developed, the impacts of which are not yet fully known.

In dementia, 'ethics' is often associated with questions of how to act at the end of life, for example in making treatment decisions, in the use of advance directives and in palliative care. However, ethical issues also arise in many other circumstances. Examples include general attitudes towards people with dementia, day-to-day decision making, the needs of carers, managing risks, covert medication, truth-telling and many other issues. There are also important ethical questions about whether and in what circumstances we should ask or allow people with dementia to participate in research once their capacity to give informed consent has become impaired.

To inform its deliberations, the Working Party would like to seek the views of people with dementia, carers, those working in health and social care, policy makers, academics, researchers and members of the public. The views expressed and experiences described will be given serious consideration by the Working Party when it is drafting its report. The Nuffield Council is particularly interested in developing ethical principles to inform approaches to issues arising in relation to dementia. As such, we would hope that our work will complement the national dementia strategy of the Department of Health in England, due to be completed in summer 2008, which will focus on raising awareness, early diagnosis and intervention, and improving the quality of care.¹

This consultation document aims to provide background information on some of the ethical issues that arise in connection with dementia. At the end of each short section there are a number of questions; these are also reproduced in full at the beginning of this document. **Please feel free to respond to as many or as few questions as you wish.** Some questions may seem particularly relevant to people with direct personal or family experience of dementia while others may seem more appropriate to professionals or academics working in this area. There is also a final section in which you will have the opportunity to raise any other issues that have not been covered.

1 http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/DH_079329.

Differences within the UK

There are significant differences between England, Wales, Scotland and Northern Ireland, in their legal systems and in their arrangements for providing health and social care. In particular, the *Mental Capacity Act 2005* applies only to England and Wales, while the *Adults with Incapacity (Scotland) Act 2000* applies in Scotland. There is currently no specific legislation in Northern Ireland relating to decision making for adults who lack capacity. In terms of the provision of services, no charges are made in Scotland for personal care (practical help other than nursing care) for those aged 65 and over, while in England, Wales and Northern Ireland recipients may be required to pay for their care depending on their financial circumstances. In this consultation paper we are keen to hear from respondents from all over the United Kingdom, and we would welcome comments on your experiences of the differences between these various systems.



What is dementia and how is it experienced?

What is meant by dementia?

The term *dementia* may be thought of as referring simply to a medical condition. In this consultation we would like to look more broadly at the effects of dementia and consider both the medical aspects and the attitudes and personal experiences of all those involved. These include the experiences of people with dementia themselves, their families and unpaid carers, those involved in delivering and managing health and social care, support organisations, other interested parties (for example, faith-based groups) and society as a whole.

Medical and psychosocial aspects of dementia

Dementia is what is called a syndrome: it is a condition characterised by a number of signs and symptoms, such as memory problems, changes in behaviour and communication difficulties, rather than a single disease. A person with dementia will experience a progressive, and usually irreversible, decline in their mental abilities as a result of damage to their brain. This damage can have many causes. Alzheimer's disease is the commonest and best known cause but there are many others, such as vascular dementia, Lewy body dementia, prion disease and fronto-temporal dementia. In this document we will use the term *dementia* to describe the effects of all these different causes of brain damage. It is important to note that there are degrees of overlap both in the underlying disease processes and in their effect on the person with dementia. This consultation, however, does not cover temporary and reversible brain damage.

The experience of dementia has a major impact both on people with dementia themselves and on the social and caring networks in which they live. The impact can be very different for different people. The experience of dementia is shaped by the particular form the dementia takes, by people themselves including their past experiences, beliefs and values, and by their social and caring networks. High quality care therefore needs to incorporate biological, psychological, social and spiritual aspects. While there are, as yet, no therapies capable of reversing the underlying degeneration of brain cells, the quality of life of people with dementia and of their carers may be improved both with medication and through good general care and support. The main drugs currently licensed in the UK are 'cholinesterase inhibitors', which in some people may temporarily improve cognitive ability. Information and advice, support groups, psychological therapies to improve confidence, practical help in the home, and assistive technologies also all have a role to play in enabling people with dementia to continue to live their lives in the way they wish.

Prevalence of dementia

Social and economic changes, public health measures and medical advances have resulted in people in the UK and many other countries living longer than they used to do. Between 1971 and 2006 the number of people over 65 years old in the UK grew from 7.4 million to 9.7 million.² The number of people living to age 85 and over is also increasing, and it is predicted that these trends will continue.³

At present, it is estimated that 700,000 people in the UK have dementia.⁴ The chance of developing dementia becomes greater the older a person is: while 1% of people aged 60-64 have dementia, this rises to 25% of those over 85. Consequently, the number of people with dementia is increasing and is expected to increase further in the future. As the population ages over the next few decades, it is forecast that the number of individuals living with dementia in the UK could more than double to 1.7 million by 2051.⁵

The experience of dementia

Although dementia is progressive, and cognitive function generally declines, the rate at which this happens varies enormously between individuals, even between people with the same type of dementia. Some people die within one or two years of the first symptoms, whereas others may live for 20 years or longer and die as a result of other conditions. Not only is the rate of change highly variable but so are the precise symptoms. Memory impairment is often, but not always, the first sign (although mild memory problems are common as people grow older and are not usually a sign of dementia). Other symptoms that may develop over the course of the condition are: language impairment, disorientation, difficulties with attention, reasoning and visual perception, behaviour and mood changes, difficulties with activities of daily living, and behaviour that is out of character. A particular person's symptoms and behaviour may often fluctuate from day to day or within a day. People with dementia may also have other long-term conditions, such as arthritis, that affect their quality of life but that are not part of the dementia itself.

As the disease progresses, the person is likely to need increasing support and may be at risk of 'wandering' and getting lost, leaving taps running or forgetting to turn off appliances. Later-stage symptoms of dementia include an inability to recognise familiar objects, surroundings or people, increasing physical frailty, difficulty in eating and swallowing, weight loss, incontinence and gradual loss of speech. Independent living can become problematic or impossible as the symptoms become worse.

An individual's personal experience of dementia will be influenced by many factors, including, for example, the direct effects of the dementia itself, emotional responses to these effects, and the behaviour of others. First-hand accounts of the experience of having dementia demonstrate that even where the condition has progressed to a point where it becomes difficult to express opinions or wishes, people may continue to have insight into their condition and circumstances.⁶ People with dementia have described their loss of confidence and distress at not being able to do things they were previously good at. However, some people have also noticed positive changes about themselves such as the learning of new skills, expansion of their creative side, valuing their time and making new friends.⁷ The Internet has enabled people to share their experiences, and to support each other more easily; for example, the Alzheimer's Society website hosts an online community for people with all types of dementia and their carers, family and friends to discuss all aspects of the condition.⁸

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 by people with dementia and those caring for them?

Q2

From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

Ethnic, cultural and social factors

Moral understandings of dementia and care for people with dementia are based on our worldview, influenced as it may be by cultural and religious factors. For example, there may be differences in values, beliefs and moral codes between people of different ethnic and cultural groups. These can affect how people with dementia are understood and cared for by their family members and other carers. Although difficult to generalise, it has been reported that some ethnic groups consider dementia more as part of the normal ageing process and less as a disease than other ethnic groups.⁹ For this reason and others, including rates of early detection, differences in concepts of and vocabulary for dementia, and the availability and type of support services, there may be differences between ethnic groups in the level of medical and other support sought and provided.¹⁰ Other social factors, such as gender, level of education, income, participation in the labour market and socio-economic status, may also play a role in how people experience dementia and how they access services.¹¹

Ethnic, cultural and social differences may affect views on both family and societal obligations for caring for people with dementia and what society owes them and their carers. They may also affect how carers find meaning in caring for their partners or elders with dementia. Individual, cultural and ethnic differences and prejudices can potentially result in difficulties and conflicts between people being cared for, their families and professional carers.

Q3

From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

Q4

What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Developments in scientific understandings of dementia

There have been major developments in recent decades in scientists' understanding of the physical changes in the brain associated with dementia. For example, a central theory as to the cause of Alzheimer's disease is that an imbalance between the production and clearance of the protein beta-amyloid in the brain is the starting point for changes that lead to the death of brain cells. This theory is leading to the trial of anti-beta-amyloid drugs which, if successful, could potentially stop the disease developing further.¹² The theory, however, is tentative at this stage and the new drugs are being developed using animal models that might not be accurate models for what happens in the human brain. Thus, while there are many promising developments in the understanding of the physical changes in the brains of people with Alzheimer's and other dementias, the emergence of new therapies may be some way off.

While headlines tend to focus on the possibility of scientific research leading to new treatments for dementia, progress in our understanding of the physical causes of dementia may also lead to more appropriate general care. For example, better understanding of the physical changes underlying the symptoms of dementia, such as memory loss, agitation or apathy, may enable those caring for people with dementia to respond more appropriately to behaviour they find distressing or difficult. Moreover, better understandings of the interactions between different conditions may lead to improvements in general healthcare: it has recently been argued, for example, that there is a direct link between relatively common infections, such as urinary tract infections, and cognitive decline, hence reinforcing the importance of treating such infections promptly and appropriately in people with dementia.¹³ Improved imaging techniques may permit both earlier diagnosis (see below) and make it possible to distinguish reliably between different forms of dementia, leading to more appropriate care.¹⁴

Q5

What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

Diagnosis

Some change in memory and other cognitive abilities is quite common as people get older. Such changes can be early signs of dementia but they need not be. In many cases people show relatively small impairment without going on to develop the more profound decline that is diagnostic of dementia. The term 'mild cognitive decline' or 'mild cognitive impairment' (MCI) is sometimes used to refer to such changes. In addition to recognising cognitive changes as diagnostic indicators, there is increasing emphasis on the use of new technologies such as brain imaging or detection of biochemical changes in the blood to try to diagnose the earliest possible stages of dementia.¹⁵

The issue arises as to whether or not it is beneficial to encourage diagnosis of dementia as early as possible. The answer to this question has implications both for the individuals involved and those concerned in their care. The advantages of seeking an early diagnosis of dementia include: identifying treatable causes of cognitive decline (such as under-functioning of the thyroid gland); enabling appropriate advice, information, support and treatment to be offered as early as possible; helping people to access financial support, and services; ensuring that people with dementia are able to take a full part in planning for their own future; and for some people it may be reassuring to be given a diagnosis to account for changes in themselves that they might have noticed.¹⁶

One major disadvantage of attempting an early diagnosis is the possibility that it may be wrong: people may be given a diagnosis of dementia when they are experiencing only 'mild cognitive impairment' which may never develop into dementia. A further complication is that there may be significant numbers of people whose brains show the changes typical of Alzheimer's disease but who experience few or none of the symptoms of dementia.¹⁷ Other suggested disadvantages of early diagnosis are that it may distress the person at a time when there is little of use that can be done, or that the person may suffer from the stigma that can be attached to the diagnosis. Such concerns may become particularly relevant if in the future it becomes possible to attempt a diagnosis (for example through blood tests or imaging) before the person experiences any symptoms.

Q6

Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

Stigma and dementia

Stigma may affect both people with dementia themselves and professionals working in dementia services. Dementia often has negative associations, particularly in relation to its later stages. A public perception of dementia care services may be that they lack professional credibility and status. It has also been suggested that the fact that dementia is seen both as a mental illness and as an illness of old age may influence the way services and those who use them are regarded.

Individuals may fear that a diagnosis of dementia will lead to discrimination by family members, friends, health professionals, and even society as a whole. Such discrimination may lead to people with dementia being perceived as different and excluded from everyday life and activities simply on the basis of their diagnosis. This perceived stigma, combined with fears about how people with dementia are valued and the standards of care they receive, may also be an obstacle to those seeking appropriate care, treatment, and support.

Q7

In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Q8

What part, if any, does stigma play in dementia care?

Q9

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



- 2 National Statistics (2007) *Ageing*, available at: <http://www.statistics.gov.uk/ci/nugget.asp?ID=949>.
- 3 National Statistics (2005) *Older People: 20 million aged 50 and over*, available at: <http://www.statistics.gov.uk/ci/nugget.asp?id=1263>.
- 4 Knapp M and Prince M (King's College London and London School of Economics) (2007) *Dementia UK* (Alzheimer's Society).
- 5 *Ibid.*
- 6 For example, see Henderson CS (1998) *Partial View: an Alzheimer's journal* (Dallas: South Methodist University Press).
- 7 Alzheimer Scotland – Action on Dementia *Don't make the journey alone – A message from fellow travellers*.
- 8 The online community website is called 'Talking Point' and is available at <http://www.alzheimers.org.uk/talkingpoint>.
- 9 Mackenzie J and Coates D *Understanding and Supporting South Asian and Eastern European Family Carers of People with Dementia* (Bradford Dementia Group); for further details see <http://www.bradford.ac.uk/health/dementia/research/supporting.php>.
- 10 La Fontaine J, Ahuja J, Bradbury NM, Phillips S and Oyebode JR (2007) Understanding dementia amongst people in minority ethnic and cultural groups *Journal of Advanced Nursing* **60**: 605–14.
- 11 See, for example, Alzheimer's Association (2008) *Alzheimer's Disease Facts and Figures*, p10.
- 12 Blennow K, de Leon MJ and Zetterberg H (2006) Alzheimer's disease *Lancet* **368**: 387–403.
- 13 Perry VH, Cunningham C and Holmes C (2007) Systemic infections and inflammation affect chronic neurodegeneration *Nature Reviews Immunology* **7**: 161–7.
- 14 Ceravolo R, Volterrani D, Gambaccini G *et al.* (2003) Dopaminergic degeneration and perfusional impairment in Lewy body dementia and Alzheimer's disease *Neural Sci* **24**: 162–3.
- 15 Waldemar G, Dubois B, Emre M *et al.* (2007) Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline *European Journal of Neurology* **14**: e1–e26; Ray S, Britschgi M, Herbert C *et al.* (2007) Classification and prediction of clinical Alzheimer's diagnosis based on plasma signalling proteins *Nature Medicine* **13**(11): 1359–62.
- 16 Information is adapted from Alzheimer's Society Factsheet: *Diagnosis and assessment*, available at: <http://www.alzheimers.org.uk/factsheet/426>.
- 17 For further details see information about the Medical Research Council Cognitive Function and Ageing Study, available at: <http://www.cfes.ac.uk/pages/neuropathology/index.html>.



Person-centred care and personal identity

Person-centred care

The idea of *person-centred* care developed as a response to what was seen as the over-medicalisation of dementia: that is, an approach to dementia which mainly emphasised physical symptoms, diagnosis and treatment with drugs.¹⁸ Person-centred care could be described as more of a 'psychosocial' approach, focusing on individuals' personal experiences, their relationships, and their uniqueness as persons. The neurologist Alexander Luria, for example, suggested that "A man does not consist of memory alone. He has feeling, will, sensibility, moral being ... It is here ... that you may touch him and see a profound change".¹⁹

Despite some uncertainty concerning its exact meaning in practice,²⁰ person-centred care is now a notion that is used widely. For instance, the recent national guidelines on dementia care for England and Wales highlighted the importance of being person-centred,²¹ as did the Department of Health's *National Service Framework for Older People* some years earlier.²² A recent review of person-centred care for people with advanced dementia reiterated the lack of consensus on a precise definition, but put forward the following: "Person-centred care has been defined as supporting the rights, values, and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behaviour, even if it is difficult to interpret; maximising each person's potential; and sharing decision making."²³

There is also a growing interest in palliative care in connection with dementia. While palliative care is often thought to refer only to care given at the very end of life, the approach can be applicable as soon as a life-threatening illness has been diagnosed.²⁴ Palliative care emphasises the importance of looking after the whole person, suggesting that we should think of the individual as a physical, emotional, social and spiritual being. By emphasising that all these aspects of personhood deserve attention, the palliative

care approach combines concern for physical symptoms with recognition of mental and spiritual needs. It may therefore be seen as combining the traditional medical approach with that of person-centred care. The two approaches – person-centred and palliative care – also complement one another by stressing the importance of both living and dying well.²⁵

These approaches have tended to draw attention to the importance of the experiences of people with dementia themselves.²⁶ Whilst in the past the personal experience of people with dementia may have been undervalued, there is now increasing evidence in favour of an inner life continuing, even into the more severe stages of dementia. Recognition of this inner, personal experience does, however, raise issues for those caring for people with severe dementia.

First, there is the question of finding out what exactly this experience is in any particular instance. Given that we cannot always know the person's wishes, desires and other relevant aspects of their inner life because, as dementia progresses, he or she may not be able to communicate these directly, we need to pay attention to other aspects of the person. For example, we can attend to the person's physical gestures and needs, and pay attention to the views of those who know the person best. That is, we must respect the biological realities as well as the social context and relationships of the person.

Secondly, an emphasis on the person's experience *now* might perhaps undermine the importance of the person's *previous* views. The potential clash between the person's current and past views has been described as a difference between their *experiential* interests (what they are experiencing now) and their *critical* interests (which have shaped how they wish to live their lives).²⁷ This issue is considered in Section 3 below, and addressed in question 13.

Thirdly, as we increasingly recognise the existence and importance of such an inner life, questions about moral responsibility may also arise. Aggressive behaviour on the part of someone with severe dementia, for example, may be perceived by some as a symptom of the dementia resulting directly from the brain damage, but by others as 'bad' behaviour for which the person is to some degree morally responsible.

These problems are not only theoretical. A person, for example, with severe dementia might at times behave in a way which he or she would previously have regarded as undignified and distressing. Carers therefore face the dilemma of deciding whether they should allow the behaviour (which currently seems to cause the person no concern) to continue, or whether to upset the person in an attempt to honour his or her earlier wishes and values. Another example is where the person with severe dementia suffers from a potentially life-threatening illness. The view taken of personhood may affect the way in which we think about treatment decisions in such a case, and how we manage other difficult or sensitive situations.

Q10

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

In answering this, you may wish to consider some of the following areas: the focus on bodily, mental or spiritual aspects of the person; social context and social relationships and their contribution to the individual's personhood; the priority to be given to previously expressed wishes and beliefs as compared to current experience.

Personal identity

All humans evolve and change over time, as do the relationships they have with others. While dementia will commonly affect an individual's mood and behaviour, in many cases family and friends will continue to recognise typical personal characteristics despite the progression of the disease. In some cases, however, dementia may lead to such profound changes within the individual that some would argue that they have in effect become a different person and that relationships with that person will change as a result. Others have argued that this view bears no resemblance to how we operate in real life: for example a granddaughter would usually continue to regard her grandfather as her grandfather, even if he no longer recognises her and even if his moods and behaviour appear to have changed significantly.²⁸

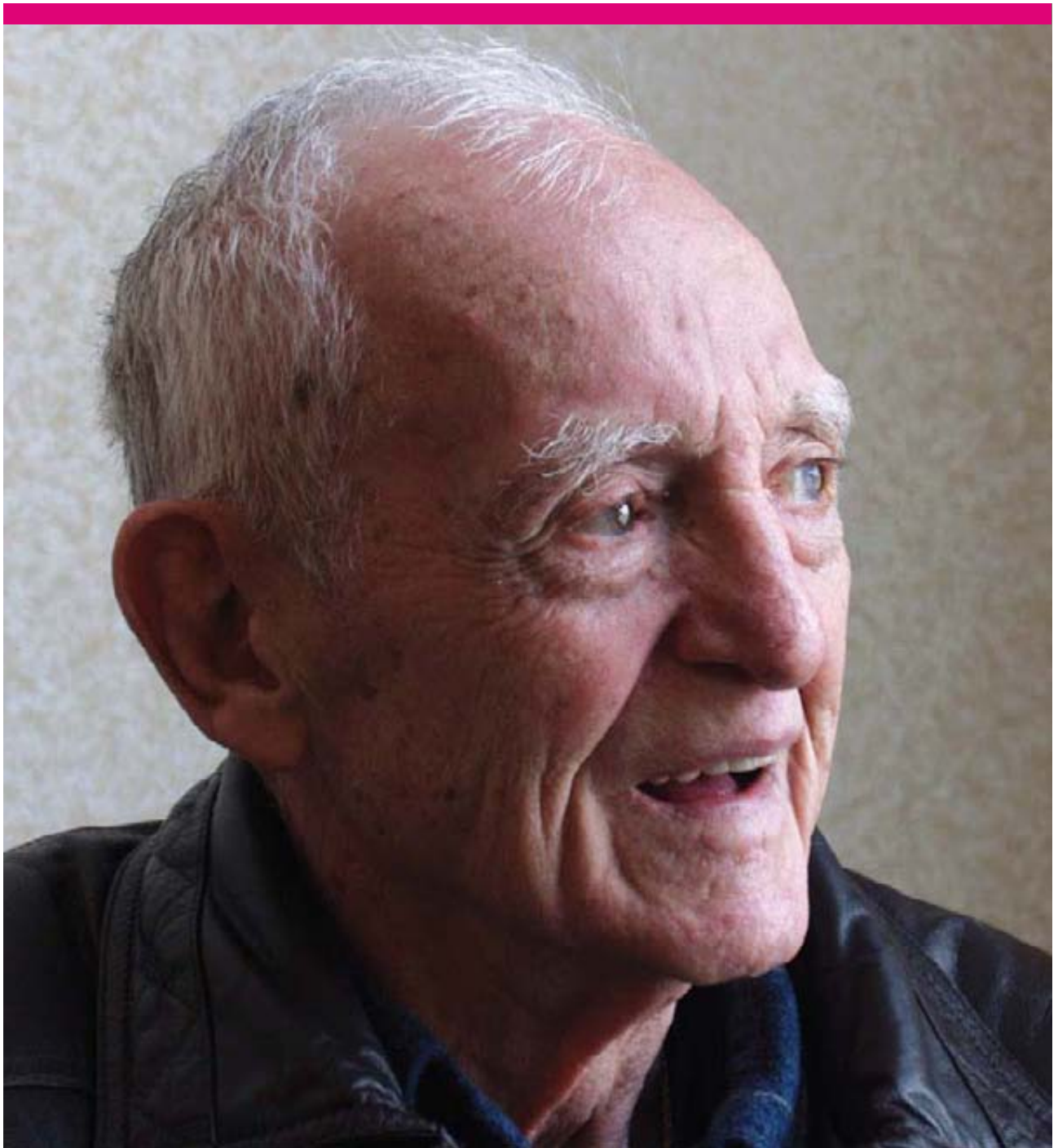
The view that a person with dementia who appears to have undergone profound changes has become a different person might have a number of implications relevant to dementia care. One possible implication is that the person's previous values and any advance decisions they have made are less relevant, or even irrelevant, because the person who held those values or made those decisions is now a different person. A second is that close family members might feel that they do not have any special duties or commitments to the person with dementia since that person is in effect a stranger.

Q11

In your view, to what extent is it correct to say that dementia changes a person's identity?

Q12

What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?



- 18 Baldwin C and Capstick A (Editors) (2007) *Tom Kitwood on Dementia: A Reader and Critical Commentary* (Maidenhead: Open University Press).
- 19 Luria AR (1976) *Neuropsychology of Memory* (Hoboken, New Jersey: John Wiley and Sons), pp250-2.
- 20 Brooker D (2004) What is person-centred care for people with dementia? *Reviews in Clinical Gerontology* **13**: 212-22.
- 21 National Collaborating Centre for Mental Health (2007) *A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care. National Clinical Practice Guideline Number 42* (Leicester and London: The British Psychological Society and Gaskell). Also available at: www.nice.org.uk/CG042.
- 22 Department of Health (2001) *National Service Framework for Older People* (London: Department of Health).
- 23 Edvardsson D, Wimblod B and Sandman PO (2008) Person-centred care of people with severe Alzheimer's disease: current status and ways forward *Lancet Neurology* **7**: 362-7.
- 24 See, for example, the World Health Organization definition of palliative care, "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (available at <http://www.who.int/cancer/palliative/definition/en/>).
- 25 Small N, Froggatt K and Downs M (2007) *Living and Dying with Dementia: Dialogues about palliative care* (Oxford: Oxford University Press).
- 26 Sabat SR (2001) *The Experience of Alzheimer's Disease: Life through a Tangled Veil* (Oxford and Malden MA: Blackwell).
- 27 Dworkin R (1993) *Life's Dominion* (London: Harper Collins).
- 28 For a discussion of these issues see, for example, Harvey M (2006) Advance directives and the severely demented *Journal of Medicine and Philosophy* **31**: 47-64.



Making decisions

Decision-making capacity

It is a long-established moral and legal principle that adults who are capable of doing so are entitled to make their own decisions about their healthcare. In particular, they are entitled to refuse any medical investigation or treatment, even life-saving treatment, and to make choices between different treatment options where these are available. The same general principle applies to areas of personal welfare: for example, adults capable of doing so are entitled to decide where they live, what they eat, and how they spend their time, whatever others think of their choices.

The approach taken by the law in this area focuses on decision-making capacity. The *Mental Capacity Act 2005* provides a legal framework for decision making in England and Wales in cases where individuals do not have the capacity to make their own decisions. The relevant statute in Scotland is the *Adults with Incapacity (Scotland) Act 2000*. There is, as yet, no Act governing this area in Northern Ireland.²⁹ Although there are many differences in detail between the English/Welsh and Scottish Acts, they take broadly the same approach. Under both Acts, people are held to lack legal capacity in connection with a particular decision if they are incapable of making, understanding or communicating that decision.³⁰ Both Acts also emphasise that capacity is decision-specific: an individual can lack capacity to make one decision but still retain sufficient capacity to make another decision. All reasonable attempts must be made to help people make their own decisions.

Best interests and benefit: the law

Where an individual lacks capacity to make a particular decision (and has not made an advance decision that is valid and applicable – see section on advance directives below), then in England and Wales the Mental Capacity Act specifies that others, such as family, friends, or health and social care professionals, must act in the individual's 'best interests'. There is no definition of best interests in the Act, but it includes a checklist of what should be considered when judging best interests, including the person's "past and present wishes and feelings", and "the beliefs and values that would be likely to influence his decision if he had capacity". Nor does the Act spell out *who* should take particular decisions: rather it states that people act lawfully if they reasonably believe that they are acting in the incapacitated person's best interests.

In Scotland, the Adults with Incapacity (Scotland) Act uses slightly different language from the Mental Capacity Act, stating that any intervention must benefit the adult, in a way that could not be achieved without the intervention. When deciding whether an intervention is justified, the Scottish Act suggests that account should be taken of "the present and past wishes and feelings of the adult" and also of the views of those closely involved with the individual.

Best interests and benefit: dilemmas

Both Acts refer to "past and present" wishes as relevant factors in determining what intervention or care is appropriate. However, situations may arise where an individual's past and present wishes differ significantly – and may even seem to be mutually contradictory. Two quite different approaches are, in theory, possible in such cases:

1. The focus should be entirely on the *past* wishes and values of individuals, resolving any conflicts in favour of past views, expressed when they had capacity. Those in favour of such an approach may see life as a narrative in which it is very important to individuals to be able to retain control over the shape of their lives as a whole.³¹
2. The focus should be entirely on people as they are when the judgment of best interests needs to be made, regardless of what they said or believed in the past. This approach emphasises the importance of meeting current physical and emotional needs, and acknowledges that people with severe dementia are still aware of their surroundings and may see their changed situation from a new perspective.³²

Q13

When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

While in some cases, it will be absolutely clear that a person either retains or lacks capacity to make a particular decision, there will be other situations where a person's capacity is borderline and where different professionals come to different views on this issue. These borderline cases may have different outcomes, depending on whether the person falls just on one side of the 'line', or just on the other. For example, if an individual is judged to be just capable of making his own decision he must be free (according to the law) to make even a decision others believe to be (seriously) unwise. On the other hand, if he is judged to (just) lack capacity to decide, his decision can be overruled by carers on the basis of their assessment of his best interests. Yet the actual difference in the person's decision-making capacity between these two scenarios may be very small.

One possible approach in cases of doubtful capacity might be to respect the person's expressed wishes unless they are demonstrably harmful, in order to avoid the risk of intervening too soon. On the other hand, it might be argued that failing to intervene leaves people vulnerable to making unwise decisions which could jeopardise their own future wellbeing.

Q14

What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

Decisions about best interests become particularly difficult when the decision to be made concerns life-sustaining treatment. A judgment about best interests and the withdrawal or withholding of such treatment involves factors such as the likelihood of treatment being successful and the side effects or burdens the treatment might impose. Some are concerned that this may require a doctor to make a judgement about the objective value, and not only the subjective quality, of a person's life.

Q15

How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

Welfare attorneys: the law

Under both the Mental Capacity Act and the Adults with Incapacity (Scotland) Act, individuals who are still able to make their own decisions may nominate someone they trust, typically a close relative, to be a welfare attorney (also known as the 'donee' of a 'lasting power of attorney' under the Mental Capacity Act).³³ The attorney will be able to take decisions on their behalf if they lose capacity at a future point in time, but will have no power before loss of capacity. Individuals may choose how much power to give their welfare attorneys: they may choose to restrict the areas in which the attorneys can make decisions, or may specify that the attorneys can take any health or welfare decision on their behalf. The Mental Capacity Act explicitly states that the power granted to an attorney may include the power to refuse life-sustaining treatment, while the Adults with Incapacity (Scotland) Act is silent on this point.

However, welfare attorneys do not have complete freedom of action: they are obliged by law to act in the individual's best interests (Mental Capacity Act) or be "satisfied that the intervention will benefit the adult" (Adults with Incapacity (Scotland) Act). Conflicts may arise in cases where the welfare attorney and health or social care professionals do not agree about the individual's best interests. This could occur in cases where there are different schools of thought about appropriate care, for example in the use of particular drugs to control challenging behaviour. It could also occur in cases where the individual, before loss of capacity, had held strong views about healthcare which differed significantly from mainstream opinion. The frequency of such conflicts between professionals and attorneys may depend on the extent to which professionals feel it appropriate to devolve more minor decisions entirely to attorneys, reserving any challenge to decisions on more substantial matters.

In England and Wales, the Mental Capacity Act *Code of Practice*³⁴ offers some guidance on what health professionals should do if they disagree with a welfare attorney's decision, suggesting that they should discuss the case with other medical experts or get a formal second opinion before discussing the matter further with the attorney. If agreement still cannot be reached, the *Code of Practice* suggests that the matter should then go to the Court of Protection. In Scotland, the Adults with Incapacity (Scotland) Act similarly specifies processes to be followed in the case of disagreement between the attorney and the responsible doctor.

Welfare attorneys: dilemmas

In theory, there are a number of possible approaches to decision making when there is disagreement between health professionals and welfare attorneys as to the best interests of a person without capacity. One approach would be for a decision by a welfare attorney to refuse treatment to be final, in the same way that the decision of an adult with capacity is final. Another would be for the welfare attorney's view to prevail unless the matter were very serious indeed (for example concerning life-sustaining treatment). A third would be for the health professionals' decisions, at least if supported by a second opinion, to be final. A fourth approach could involve the use of mediation or other forms of alternative dispute resolution, while a fifth would be always to involve a court in cases of significant disagreement between the relevant attorneys and health professionals.

Q16

What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?



Advance directives: the law

Advance directives (called *advance decisions* in the Mental Capacity Act) are statements made by people with capacity about how they want to be treated in the future if they become ill and at the same time lack capacity to give or refuse consent. For example people might state in their advance directive that if in the future they have dementia and are no longer able to recognise, or hold a conversation with, their close relatives, then they refuse life-extending treatments, such as antibiotics as treatment for a chest infection. Under the Mental Capacity Act, an advance decision to refuse treatment must be honoured if it is valid and applicable to the circumstances of the case. In Scotland, the Adults with Incapacity (Scotland) Act does not refer to advance directives; however, the relevant part of the Scottish Code of Practice states that advance directives refusing particular treatment are "potentially binding".³⁵ There is no case-law on this issue in Northern Ireland; however, British Medical Association guidance to doctors suggests that it is likely that earlier English case-law, upholding a valid and applicable advance refusal of treatment, would be followed by a Northern Ireland court.³⁶

Advance directives: dilemmas

Some people believe that advance directives provide an effective way of extending individual choice to situations when capacity is lost, and that everyone should be encouraged to make such advance directives to cover future possible situations. Others believe that advance directives have little value. They may fear that following such directives might lead to decisions that are not in the person's best interests or may be sceptical that people are sufficiently able to imagine a future situation in which they lack capacity.

Case example: Mrs A³⁷

Earlier in her life, Mrs A made it clear that she would not value life with dementia and if, at some point in the future, she were to develop dementia and lose capacity to make her own decisions, she would not want any medical treatment which might prolong her life. Mrs A goes on to develop dementia. She appears to be extremely contented, spending her days happily reading random pages of a detective story, drawing the same picture repeatedly, and eating her favourite foods. Difficulties may arise in determining whether her current or past preferences should dominate when making critical decisions about her healthcare if she is not able to form or communicate her views herself.



There are broadly three positions that could be taken with regard to a valid advance directive:

1. The advance directive (for example, a refusal of antibiotics) should be respected even if the relevant carers believe that to respect it goes against the person's current best interests.
2. The advance directive should be ignored: the person should be treated in their best interests as judged by the relevant carers (both family and professional).
3. The advance directive should be taken into account as one piece of evidence about what is in the person's best interests but weight should also be given to other considerations, such as whether the person appears to be generally happy (see the case of Mrs A above). According to this approach the final decision involves making a judgment about what is best, taking into account a number of considerations of which the advance directive is only one.

Q17

What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

Your general views about legislation governing mental incapacity

The *Adults with Incapacity (Scotland) Act 2000* has now been in force for several years. The *Mental Capacity Act 2005* came fully into force in October 2007.

Q18

What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

- 29 Guidance issued by the British Medical Association suggests that where an individual lacks capacity, treatment decisions will be the responsibility of the treating clinician, on the basis of the person's best interests: BMA (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment* (Oxford: Blackwell Publishing), pp69-70. This is based on the House of Lords case *Re F (mental patient: sterilisation)* [1989] 2 All ER 545.
- 30 While the *Adults with Incapacity (Scotland) Act* refers simply to "making" the decision, the *Mental Capacity Act* further breaks down the process of making decisions into the processes of "understanding and retaining" the relevant information and then "using and weighing" it to come to the decision.
- 31 eg Dworkin R (1993) *Life's Dominion* (London: Harper Collins), chapter 8.
- 32 eg Dresser R (1995) Dworkin on dementia: elegant theory, questionable policy *Hastings Center Report* 25(6): 32-8.
- 33 There is, as yet, no equivalent provision in Northern Ireland.
- 34 Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*, chapter 7.
- 35 Scottish Government (2002) *Adults with Incapacity (Scotland) Act 2000 Code of Practice: for persons authorised to carry out medical treatment or research under Part 5 of the Act*, paragraph 2.29.
- 36 BMA (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment* (Oxford: Blackwell Publishing), p69.
- 37 Based on the case of 'Margo', as described in Firluk A (1991), Margo's logo, *JAMA* 265(2): 201, and debated further in Dworkin and Dresser, notes 31 and 32 above.



Aspects of care and support

Ethical dilemmas in care

A number of recent reports have raised issues around standards of care for people with dementia, whether living in their own homes or in supported residential care. The Alzheimer's Society report *Home from Home*, for example, while recognising examples of excellent practice, concludes that "many homes are still not providing the level of person centred care people with dementia deserve".³⁸ More generally, the National Audit Office has suggested that the care of people with dementia has, to date, not been seen as a priority by health and social services, and that as a result the provision of services has been inconsistent and poorly planned.³⁹ In response, the Department of Health in England has promised to develop a national dementia strategy, one of the key aims of which will be to encourage high quality care standards.⁴⁰

Many of the factors raised by these recent reports relate to managerial and financial matters, such as how services are prioritised, organised and signposted and how staff are deployed. In addition to these issues which the Department of Health's strategy will be seeking to address, however, there are many complex ethical questions that arise when caring for and supporting a person with moderate or severe dementia. These include dilemmas around truth-telling, risk-taking, restraint, and competing interests. It is on these issues that this section of the consultation document will focus.

Truth-telling

At first glance, it may seem self-evident that responding truthfully to the person for whom one is caring will always be the right thing to do. However, there are strong conflicting opinions about the question of truth-telling in certain circumstances in dementia care. On the one hand, it has been argued that failing to tell a person the factual truth not only demeans both parties, but may also serve to exacerbate the symptoms of dementia: if a person's grip on reality is already weak, failing to tell the truth may undermine that grip still further.⁴¹ Similarly, it could be argued that the fact that individuals are made more vulnerable by dementia means that the duty to treat them with respect by always telling the truth is strengthened. On the other hand, telling the factual truth may sometimes result in considerable and perhaps unnecessary distress, for example, when a person with dementia cannot remember that her husband has died and repeatedly asks where he is. Each time carers respond truthfully may cause her to re-live the first moments of her grief.

Another type of example over which opinions vary is when a person with dementia will not sit down to breakfast because she believes that she has to take her children (who are long grown-up) to school. Some argue that telling her a well-intentioned lie, such as reassuring her that her children are already safely at school, would undermine her relationship with reality. Others claim that the lie would be in her best interests: the reassurance would enable her to relax, stop worrying about her children, and eat the food she needs. Yet others, suggest that 'truth' is not a simple matter of words: that what is actually being expressed in this scenario is anxiety and that a 'truthful' response would be to recognise the anxiety and offer reassurance.

Similar problems of truth-telling also arise when considering whether it is acceptable to disguise medication in food or drinks.

Q19

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 and risk

The degree to which people with dementia, especially those living in residential care, should be permitted to take risks as part of their everyday lives is a key ethical problem for those involved in their care. In their own daily lives, individuals have very different attitudes to risk, from how they cross the road, drive a car or engage in dangerous sports, to how they plan their careers or invest their money. However, virtually everyone will choose to accept *some* degree of risk both as an inevitable part of living in society and in order to do things that they enjoy.

When people have reduced capacity to make their own decisions, there is a natural tendency for carers (family, friends and professionals) to attempt to reduce risks to a minimum. On one view this will always be the right thing to do: exposing someone else to avoidable risks (sharp knives, busy roads, falls) might be regarded as simply irresponsible. On the other hand, the attempt to remove all hazards of daily life may itself risk compromising the quality of that life. Recent court judgments in Germany, for example, have considered whether it would be acceptable to impose bed rails, or other restraining measures, on unwilling residents in order to avoid the risk of a fall. They concluded that nursing homes had duties to preserve the independence and self-determination of their residents, as well as their physical safety, and therefore held that such restrictive measures were not permissible if rejected by the individual concerned.⁴²

Staff concerns about risk may also arise in connection with sexual relationships as mental capacity declines. The Alzheimer's Society notes that dementia does not necessarily have a negative impact on people's sexual feelings and that many couples continue to find considerable mutual support and comfort through physical intimacy, even when other forms of communication have become difficult.⁴³ Those working in care homes, however, may sometimes be concerned that sexual relationships risk becoming abusive, particularly if the partner is not well-known to them or has not been in an established long-term relationship with the resident.

Q20

In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

Restraint

The arguments against using restraint are powerful: restraining people constitutes a significant overriding of their autonomy, not only preventing them from doing what they wished to do, but often also using force to achieve this aim. Yet, at times, it might seem the best option, whether in order to protect the health and safety of the individuals concerned, to promote their overall best interests, or to protect others.

In England and Wales, the Mental Capacity Act allows the restraining of a person without capacity only when this is necessary to prevent harm to that person. Restraint must be a proportionate response both to the likelihood of the individual suffering harm and to the seriousness of that harm. Under the common law, there will also be situations where restraint may lawfully be used to prevent harm to others. In Scotland, the Adults with Incapacity (Scotland) Act specifies that "force and detention" may be used in connection with medical treatment only where it is immediately necessary, but is silent on restraint in other circumstances. However, as in England, the common law permits restraint if this is necessary to prevent immediate harm. Care homes are specifically forbidden from using restraint "unless it is the only practicable means of securing the welfare of that or any other service user and there are exceptional circumstances."⁴⁴ In addition, both Acts set out general principles for caring for people who lack capacity, specifying that anything done in connection with an incapacitated person must be the "least restrictive" of the available options.

Examples of where various forms of restraint are sometimes used in connection with dementia care include:

- using force to remove a person from one place to another: for example removing someone who is behaving aggressively in the common areas of a care home to their own room;
- 'bundling' someone in a car to take them to a day centre because, although they resist getting into the car, they always enjoy themselves when they get to the centre;
- deliberately leaving a person in a place they can't leave without help, such as a specially low or soft chair, to avoid harm from wandering; and
- sedating a person to keep them calm or get them to sleep, or giving them medication to control 'difficult' behaviour.

The examples above demonstrate the variety of reasons that may form the basis for a decision to use restraint. They also highlight the difficulties in determining whether, in any particular case, restraint may be ethically justified. The use of restraint in the day care scenario, for example, might be considered appropriate because overall it is in the person's best interests to be taken for day care. It is not clear, however, whether it is lawful under the Mental Capacity Act because the restraint does not necessarily 'prevent harm' to that individual. In circumstances where the reason for restraint is aggressive behaviour, the justification will be to prevent harm to self or others. In such cases it may be possible and preferable to avoid the harmful situation arising in the first place: for example challenging behaviour can sometimes be avoided by spending more time with the person and seeking to understand which particular triggers set off these kinds of behaviours. Action can then be taken to avoid, or minimise, such triggers in the future. This kind of approach may, however, occupy a great deal of staff time.

It has also been suggested that some forms of restraint (for example leaving someone in a low chair, or some use of sedating drugs) may be used primarily for the convenience of staff, or because of resource constraints, rather than because it is believed to be in the individual's own best interests.⁴⁵ Restraint for these purposes would appear to be unlawful under the Mental Capacity Act.

The issue of restraint also brings up the question of competing interests, particularly in the context of a care home where residents' needs may differ significantly. For example, odd behaviour on the part of one person may cause another to feel threatened, even if most people would not feel the same way. The distress experienced by the other resident will have to be taken into account when considering how to respond to the behaviour. Similarly, staff routinely have to deal with competing demands on their time, and hence have to bear in mind that extra attention devoted to one person with the aim of reducing the need for restraint has implications for the care of other residents.

Q21

Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

Education and training

Professional caregivers, both those working in residential care and those supporting people with dementia in their own homes, face dilemmas similar to those outlined above on a daily basis.

Q22

Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?



New technologies

New technologies have the potential to make a significant difference both to people with dementia and to the lives of family and friends who provide informal care. 'Smart' housing may contribute significantly to the ability of a person to live independently despite the progression of their dementia, with features such as automatic lighting to guide the individual to the bathroom, automatic cut-offs for taps and cookers, warnings about hot stoves and so on.⁴⁶ The availability of these technologies may serve to reduce risks, thus reducing the anxiety felt by family and friends about the safety of the person with dementia as well as making the person themselves feel more secure. In addition, monitoring devices may alert carers that they need to take action: for example if the person is about to leave the house and it is not safe for them to do so.

Other possible applications of technology include telemedicine devices which permit remote monitoring of a person's health, and the use of so-called tagging to enable people with dementia who are at risk from wandering to wander freely without concerns that they will get lost. It has also been suggested that the use of video surveillance in care homes may reassure relatives that their family member with dementia is being properly cared for. As this last example suggests, however, many of these technologies involve a degree of monitoring which might be regarded as an invasion of privacy. Moreover, some have been available for some years and have not been significantly adopted in practice.

Q23

What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?



The duty to care for people with dementia

In the UK, the cost of NHS and local authority social care services provided for people with dementia are estimated at £1.36 billion and £2.5 billion per year respectively.⁴⁷ However, the economic impact of dementia is much wider than these figures reveal: for the UK, the overall annual cost of dementia to the economy is estimated at over £17 billion, more than stroke, heart disease and cancer combined. This figure includes costs resulting from care provided by formal agencies and also the financial value of unpaid informal care, including lost income, provided by family and friends. The costs of supporting people with dementia are thus split between the state, people with dementia themselves (whose own financial resources will often be used to fund care) and their family and friends. The recent 'Wanless report'⁴⁸ into the funding of social care services for older people has reignited the longstanding debate as to what duties the state should accept in funding such care, and what individuals should expect to provide for themselves and their families.

As well as the issue of the size of the role to be played by the state, there is also the question of *how* any state support should be delivered. Historically in the UK, most social care support has been provided in kind: social services departments assess needs, and then either directly provide services themselves or contract with the independent sector for specified services. More recently, however, this has begun to change, particularly in England where the 'direct payments' system (under which disabled people receive the cash equivalent of their assessed care needs in order to arrange their own care) is now being expanded with many more people being offered 'personalised budgets' to pay for their own social care.⁴⁹ The Government has also recently announced that it will be producing a consultative Green Paper on reform to the adult social care system with the aim of ensuring that an affordable system is in place that will give people "greater choice and control" over their lives.⁵⁰

As the reference to "choice and control" suggests, one ethical principle underlying these developments is respect for autonomy, with emphasis being placed on individuals' rights to choose both what sort of support they would value most and who should provide it. This contrasts with a model of service provision where the individual simply has to accept whatever services are on offer. Concerns have been expressed, however, that the emphasis on choice may be overstated, with many people experiencing the need to find and employ their own carers as a burden rather than a benefit. Similar points have been made in the past in connection with 'self-funders' (those whose income or capital is too high to qualify for state support) who often end up arranging their own care with little support or advice from social services.

Different attitudes to the role of the state will clearly affect beliefs about what duties the state has towards people with dementia and their families, and how these duties should be met. Some may see the state as having a duty both to fund and provide all necessary care; some may expect the state to meet the costs of all care but not necessarily be the only, or main, provider of that care; some may expect the state to make at least a financial contribution to the costs of care; and yet others may believe that it is a duty of individuals and families to provide for their own future care needs, with the state providing only a safety net for those genuinely unable to afford the care they need.

Q24

What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

- 38 Alzheimer's Society (2007) *Home from Home: a report highlighting opportunities for improving standards of dementia care in care homes*.
- 39 National Audit Office (2007) *Improving Services and Support for People with Dementia*.
- 40 Department of Health press notice 2007/0224, 6 August 2007.
- 41 For example by Tom Kitwood: see Kitwood T (1997) *Dementia Reconsidered: The person comes first* (Maidenhead: Open University Press).
- 42 Sammet K (2007) Autonomy or protection from harm? Judgements of German courts on care for the elderly in nursing homes *Journal of Medical Ethics* **33**: 534-7
- 43 Alzheimer's Society (2006) *Physical Intimacy*: www.alzheimers.org.uk/factsheet/514.
- 44 *The Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002*, SSI 2002/114, Regulation 4(1)(c).
- 45 Commission for Social Care Inspection (2007) *Rights, Risks and Restraints: An exploration into the use of restraint in the care of older people*.
- 46 Evans N, Orpwood R, Adlam T, Chadd J and Self D (2007) Evaluation of an enabling smart flat for people with dementia *Journal of Dementia Care* **15(6)**: 33-6.
- 47 Alzheimer's Society (2007) *Dementia UK*, p xviii.
- 48 Wanless D (2006) *Securing Good Care for Older People – Taking a long-term view* (King's Fund).
- 49 Department of Health (2007) *Putting People First*, available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118.
- 50 HM Treasury (2007) *Pre-Budget Report and Comprehensive Spending Review*, chapter 6, available at http://www.hm-treasury.gov.uk/media/1/1/pbr_csr07_chapter6_227.pdf.



Section
5

The needs of carers

The impact of being a carer

Many people with dementia are cared for by one or more family members who provide them with substantial support. Some people will willingly embrace the role of being a 'carer', regarding it as a natural part of their family or social role and finding satisfaction in it. At the same time, taking on the role of a carer may have a major impact on that person's life, imposing significant financial and emotional burdens, which may also have implications for their health. The recent National Audit Office report, for example, noted that the financial costs of caring may include lost employment opportunities and lower earnings, both of which are likely to be felt life-long through lost pension entitlements. Alongside these financial effects of caring, the report commented that a key issue for many carers was "the loss of their own life as they knew it", and that depression was a common result.⁵¹ Moreover, some carers may feel that the role of carer has been forced upon them, or struggle to reconcile the idea of being a carer with their original role as spouse, son or daughter, or other relative or friend.⁵²

The impact of being a carer on any individual is likely to depend on a range of factors. Research investigating the impact of ethnicity on caring has concluded that while this has some effect on carers' experiences, so do many other factors, such as the relationship with the person being cared for, the amount of time spent caring, the nature of support required, income, education, gender, the degree of both informal and formal support available, and the carer's own perception of the caring role.⁵³

The need to support people who have taken on a role as carer has increasingly been recognised and there have been many initiatives that aim to support carers including the widespread development of self-help groups and Alzheimer's organisations. Pressure on carers, however, remains considerable, and in November 2007 the Government, acknowledging these concerns, announced a strategy called 'New Deal for Carers'.⁵⁴ Its measures aim to improve support for carers through, for example, establishing a helpline to offer advice to carers; ensuring that short-term, home-based breaks for carers are available at times of crisis; and funding the development of an 'expert carers' programme'.

What is perhaps less often recognised is the fact that the needs and interests of carers may sometimes be in direct conflict with the needs and interests of the person for whom they care. One common example of conflicting interests arises when people with dementia would prefer to stay in their own homes, with the support of a family carer, but where that carer is physically unwell, or emotionally exhausted, or has other commitments and feels unable to cope. Such situations may be made yet harder for the carer to resolve if the person with dementia has, earlier, asked the carer to promise 'never to put me in a home'.

While conflicts of interest may potentially arise in any caring situation, the difficulty increases in cases where the person being cared for has impaired capacity to make their own decisions. In such cases, the carer may be taking an active part in making decisions with and for the person they care for – decisions that may have very difficult consequences for themselves. Moreover, carers may themselves be vulnerable quite apart from their caring role: for example, it has been estimated that 68% of carers of people with dementia are over 65 and 12% are over 80.⁵⁵

Factors such as stress, conflicts of interest, vulnerability of the cared-for person and vulnerability of the carer may also lead to financial, physical and psychological abuse or neglect. Situations of abuse are not always easy to recognise by professional caregivers. Furthermore, if there is a suspicion of abuse, professionals may not know how to deal with it. They may perceive any action in relation to the problem as an intrusion into the private sphere of the family. Alternatively, the professional may think it appropriate to intervene but may underestimate the extent to which the person is still gaining some benefit from the relationship, despite the existence of the abuse.

Q25

How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

Q26

What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

The 'never put me in a home' example, cited above, demonstrates that sometimes the person being cared for and the carer may have incompatible interests. However, the situation may also arise where they have *joint* interests that may not be recognised if each is assessed only as an individual. One example is where a person with dementia is assessed as needing specialist residential care, while his wife and carer (herself very frail) is assessed as needing long-term care in a less specialist establishment. Separate assessments of their care needs might lead to their being placed in separate care homes, particularly as more specialist services are likely to be more expensive. In such cases, although each decision might individually seem to meet the assessed care needs of each person, the couple's *joint* need to be together will have been neglected.

Q27

In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a couple (or of a household), instead of concentrating solely on the interests and needs of the individual?

Confidentiality

Another area in which conflicts may arise is in that of personal confidentiality. A person with dementia has the same legal right to confidentiality (for example in relation to their health records) as anybody else. Where they have capacity to do so, they have the right to choose whether or not to allow other people, such as family members, access to that information. However, in cases where the person with dementia is no longer able to make this decision, it may be difficult for carers to take appropriate decisions on their behalf without access to confidential information. Such information might include diagnosis (for example that the person is likely to have Alzheimer's disease) or opinions on how the person's condition is likely to develop. A relative who is also a welfare attorney probably has the legal right to information that is necessary in order to inform decision making; but it is up to the judgment of health professionals how much to tell carers who are not formal welfare attorneys.

It is thought by some carers that many health professionals keep too much information confidential with regard to people with dementia and that, as a result, some carers have difficulty accessing information they need in their caring role. On the other hand, some believe that health professionals sometimes breach the confidentiality of people with dementia too readily, and share too much information with the family. Furthermore, concerns are regularly expressed about confidential information being discussed inappropriately in public places.⁵⁶

Q28

From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?



- 51 National Audit Office (2007) *Improving Services and Support for People with Dementia*, paragraph 1.10.
- 52 Goldsteen M, Abma T, Oeseburg B *et al.* (2007) What is it to be a daughter? Identities under pressure in dementia care *Bioethics* 21(1): 1–12.
- 53 Pinquart M and Sörensen S (2005) Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis *The Gerontologist* 45(2): 90–106.
- 54 Information available at: http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/DH_080168.
- 55 Cayton H (2001) Carers' lives, in *Psychiatry in the Elderly*, Jacoby R and Oppenheimer C (Editors) (Oxford: Oxford University Press), pp441–59.
- 56 See, for example, House of Lords and House of Commons Joint Committee on Human Rights (2007) *The Human Rights of Older People in Healthcare: Eighteenth Report of Session 2006–07*, HL Paper 156-I, HC Paper 378-I.



Section
6

Research

Research priorities

While there have been major advances in recent years in dementia research, the 2007 report *Dementia UK*, produced by the London School of Economics and King's College London for the Alzheimer's Society, highlighted the apparently low priority given to dementia research when compared with that devoted to other conditions. A survey of research papers on long-term conditions published since 2002, for example, demonstrated that while 23.5% were concerned with cancer and 17.6% with cardiovascular diseases, only 1.4% focused on dementia. However, these figures do not necessarily demonstrate that dementia research is ineffective: a recent article, for example, refers to "breathtaking advances in understanding the neurobiology of dementia" and the resulting "promising leads for therapies".⁵⁷

Moreover, there is an additional important issue as to how research effort, and research funding, is prioritised *within* dementia research. Research effort may be focused on improving our understanding of the processes in the brain which lead to dementia; on seeking ways to alleviate and ultimately cure the condition by developing drugs that slow down, stop or even reverse those processes; or on improving the quality of life of people with dementia now. Distinctions can also be drawn between research that is likely to help people in the very near future, and research with much longer-term aims, where benefits are most likely to be seen by future generations.

Q29

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

Involvement in research

Individuals with the capacity to make their own decisions as to whether or not to be involved in research may be involved only if they give consent. People choose to participate in research for a wide range of reasons. They may wish to access an experimental treatment before it is generally available in the hope that they will benefit. They may have altruistic reasons for participating, even where they do not expect to benefit personally. They may also find that the process of taking part in research (such as extra attention from health professionals and the sense of being involved) is enjoyable or beneficial. The ability of people with dementia to make their own decisions (if necessary with plenty of support) as to whether or not they wish to participate in research should not be under-estimated. Nor should the fact be forgotten that a person's capacity may fluctuate significantly: for example, people with dementia may have 'good' and 'bad' times of day and may be able to make their own decision if approached at the right time and in the right way.

The main aim of medical research is to gain knowledge that, it is hoped, will benefit people in the future. There is a distinction between research that has the potential to benefit those who take part in the research and that which does not. An example of research that may benefit those taking part is a trial comparing current treatment with a novel treatment. An example of research which does not have the potential to benefit those taking part is basic science research concerned with a better understanding of dementia that is unlikely to result in any improvement in management for many years.

Where individuals do not have the capacity to make their own decision about participating in research, and where the research is not likely to benefit the participant, several different approaches have been suggested:

- At one end of the spectrum, it is argued that people should *never* be involved in such research if they lack the capacity to make this decision for themselves.
- A second position is the principle that people should only be involved in research if they had, in the past, expressed a positive desire to participate through some form of advance decision. Such a decision might be specific, or it might be quite general, expressing a general altruistic willingness to participate in any relevant research that has been approved by the appropriate authorities.
- A third option is that of proxy consent. A proxy might be named by the individual in advance of any loss of capacity, or by others at the time the decision is needed. Alternatively, it has also been suggested that a proxy could be named by the individual at the *time* the consent is required, in circumstances where the individual no longer has capacity to give legally valid consent to the research proposal but does have the capacity to nominate a trusted person to make the decision.⁵⁸ Where a proxy approach is adopted, much will depend on the constraints (if any) placed on the proxy decision maker.

The law in the UK broadly adopts a proxy-based approach, but imposes varying constraints on the proxy decision maker depending both on the type of research and on where in the UK the research is taking place. A distinction is made between a 'clinical trial' (which aims to test the safety and the effectiveness of a new medicinal product) and other types of research. Clinical trials are regulated by the Clinical Trials Regulations⁵⁹ (which apply to the whole of the UK), while other forms of research are regulated in England and Wales by the *Mental Capacity Act* and in Scotland by the *Adults with Incapacity (Scotland) Act*. There is as yet no equivalent Act in Northern Ireland and hence research which does not count as a clinical trial is subject to the common law. All medical research involving human participants in the UK must also be approved by an independent research ethics committee.

All three sets of statutory requirements (the Clinical Trials Regulations, the Mental Capacity Act and the Adults with Incapacity (Scotland) Act) specify criteria that aim to protect people who lack capacity from undue risks in research. All three also require some form of consent from, or consultation with, a proxy. However, there are some differences both in language and in approach between the three pieces of legislation.

Protecting the individual from harm

- The Clinical Trials Regulations specify that there must be grounds to expect that administering the product to a person who lacks capacity will produce a benefit to the person that "outweighs" the risks, or will result in no risk at all.
- The Mental Capacity Act requires that research involving incapacitated adults must *either* have the potential to benefit the person without exposing them to "disproportionate" risks, or, if no direct personal benefit is expected, the risks must be "negligible" and anything done to the person must not be "unduly invasive or restrictive" or interfere significantly with their freedom of action or privacy.
- The Adults with Incapacity (Scotland) Act requires that the research should involve "only a minimal foreseeable risk" and only "minimal discomfort". The Adults with Incapacity (Scotland) Act adds a further proviso that if the research is not likely to benefit the individual directly, it can go ahead only if it is likely substantially to further scientific understanding, and hence improve care for others (in the future) with the same incapacity. Unlike the Mental Capacity Act, the Adults with Incapacity (Scotland) Act thus sets the same threshold for risk, regardless of whether or not the research is likely to benefit the individual.

Seeking consent

- In research governed by the Clinical Trials Regulations, consent must be given, either by individuals themselves before loss of capacity, or by a “legal representative”. In England, Wales and Northern Ireland, the legal representative may be a suitable relative or friend of the individual, or, if no such person is available, the individual’s own doctor as long as he or she is not involved in the research. In Scotland, the first choice of representative is the welfare attorney or guardian, if one has been appointed; if not, the nearest relative, or the individual’s own doctor as long as he or she is not involved in the research.
- Under the Mental Capacity Act, however, formal consent is not sought from a proxy: instead, a carer (or other unpaid person interested in the welfare of the person with dementia) must be consulted for advice as to whether the person should take part in the project. If the carer’s advice is that the person would not have wished to be involved in the research project, then the person should not be involved. If there is no appropriate unpaid carer to consult, then a person unconnected with the research must be nominated to take on this role. The person’s welfare attorney (where one has been appointed) does not have any special role in research decisions, although it is likely that such an attorney would be an obvious choice as the person to be consulted as the ‘carer’.

- Under the Adults with Incapacity (Scotland) Act, consent must be obtained from the individual’s guardian or welfare attorney or (if no such person has been appointed) from the nearest relative.

Q30

What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

Q31

Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research that you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

57 Khachaturian ZS (2007) A chapter in the development of Alzheimer’s disease research: a case study of public policies on the development and funding of research *Alzheimer’s & Dementia* **3**(3): 243–58.
58 See, for example, Kim SYH and Appelbaum PS (2006) The capacity to appoint a proxy and the possibility of concurrent proxy directives *Behav Sci Law* **24**: 469–78.
59 Full title: Medicines for Human Use (Clinical Trials) Regulations 2004, SI 2041, as amended.

Section

7

Other issues

Q32

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



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

Nuffield Council on Bioethics

28 Bedford Square

London WC1B 3JS

UK

Telephone: 020 7681 9619

Fax: 020 7637 1712

www.nuffieldbioethics.org

A shortened version of this consultation paper is also available for people who would prefer a briefer document, which may include those with dementia. Both documents can be downloaded from the Council's website: www.nuffieldbioethics.org. For printed copies, please contact the Council using the details above. Responses to the consultation can be submitted online or sent by email to: consultation@nuffieldbioethics.org.

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