Dementia: ethical issues

Nuffield Council on Bioethics
The Nuffield Council on Bioethics

• Established in 1991

• Independent body that examines ethical questions raised by advances in biology and medicine

• Contributes to policy making and stimulates debate
The Working Party

• Began work in November 2007
• Members included those with expertise in ethics, front line care for people with dementia, law, old age psychiatry and neuroscience
• Public consultation in summer 2008 received over 200 responses
• Deliberative workshop for 50 members of the public held in Birmingham
• Draft report peer-reviewed by nine reviewers
• Final report published 1 October 2009
Dementia: ethical issues
The report

Policy recommendations based on an underpinning ethical framework:

• ethical approaches to dementia care
• tackling dilemmas in day-to-day care
• decision making
• stigma and including people with dementia in society
• recognising the needs of family carers
• research priorities and participation
An ethical framework for dementia

Six ‘components’

- A methodology for approaching ethical decisions
- Two beliefs about the nature of dementia
- A set of interlinked ethical values
An ethical framework: Component 1

A ‘case-based’ approach to ethical decisions

- Identify the relevant facts
- Interpret and apply appropriate ethical values
- Compare the situation with other similar situations
An ethical framework: Components 2 & 3

Two beliefs about the nature of dementia

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

• With good care and support, people with dementia can expect to have a good quality of life – you can ‘live well’ with dementia
An ethical framework: Component 4

Promoting the interests of the person with dementia and those who care for them

1. Promoting autonomy
   Autonomy is not just about ‘rational choice’ – it includes supporting important relationships, and supporting the person in expressing their values

2. Promoting well-being
   Well-being includes moment-to-moment experiences of contentment, and also objective factors such as a person’s level of mental ability
An ethical framework: Component 5

Acting in accordance with solidarity

• The belief that people with dementia are fellow citizens and that we are all ‘fellow-travellers’
• Recognition of our mutual interdependence
• Duty to support people with dementia and to support carers in their own exercise of solidarity
An ethical framework: Component 6

Recognising the personhood of the person with dementia

- A person with dementia is the ‘same’ person, despite changes in mood and behaviour
- A person with dementia is of equal value to a person without dementia
Policy implications

• For people with dementia and carers
• For those providing health and social care services
• For those commissioning and funding services
• For wider society
• For those involved in research
Implications for people with dementia and carers

- Person with dementia to be respected as an equal, valued, person
- More support needed in dealing with daily ethical dilemmas – eg access to peer support and education
- Carers to be treated as ‘partners in care’ – implications both for how care is shared and how information is shared
- More dementia-specific guidance needed under the mental capacity legislation
Implications for those providing services

- *How* things are done is often far more important than the structure or format of services – is the person with dementia being seen as an individual valued human being?

- Crucial to have access to education and support – both in making ethical decisions and in supporting carers in making such decisions

- ‘Timely’ diagnosis – when it’s right for this particular person and their family/those close to them

- Flexible services – which meet the needs of this particular person and those of their family and friends
Implications for those commissioning and funding services

• Dementia is a medical disorder – it’s simply not acceptable to leave people without support until a crisis occurs.

• Access to services should not be determined by classifications of care: in allocating resources and in setting high standards of care, it should make no difference whether the care is classed ‘health’ or ‘social’.

• There is a wider debate about how we as a society fund good quality social services but the key issue here is access.
Implications for wider society

• Dementia needs to become an accepted visible part of our society – ‘normalised’
• We all have a role to play in tackling stigma and discrimination – not just about health and social services
  – making ‘reasonable adjustments’ for dementia when providing services in shops, cafes, leisure services etc
  – ‘dementia friendly’ buildings
Implications for research

- Need for greater clarity in how research funds are allocated
- Particular research focus on the reality of living with dementia and what kind of support helps best
- Support to enable people with dementia wherever possible to make their own decisions about research involvement – eg by appropriate adaptation of research information
Further information

www.nuffieldbioethics.org/dementia