



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

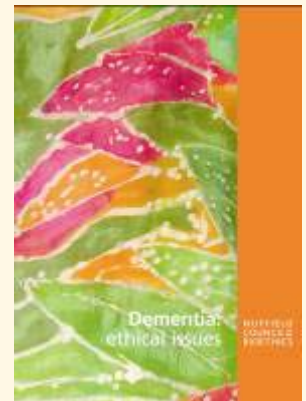
- Began work in November 2007
- Members included those with expertise in ethics, front line care for people with dementia, law, old age psychiatry and neuroscience
- Public consultation in summer 2008 received over 200 responses
- Deliberative workshop for 50 members of the public held in Birmingham
- 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