



Dementia: ethical issues


The needs of carers

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NUFFIELD
COUNCIL ON
BIOETHICS



Dementia: ethical issues

Report of the Working Party

Our recommendations
concentrating on the following themes:

- Promoting an ethical approach to dementia, in all its aspects
- Tackling the dilemmas of daily care
- Assisting decision-making
- Including people with dementia in society as a whole
- Recognising the particular needs of family members and carers
- Establishing research priorities



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Caring for people and their carers


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 relationships, and supporting the expression of personal values

2. Promoting **well-being**

Well-being includes moment-to-moment experiences of contentment, and also objective factors such as mental abilities



Demonstrating 'solidarity'

Acting in accordance with solidarity

- People with dementia are fellow citizens and we are all 'fellow-travellers'
- We need to recognise our mutual interdependence
- Our duty to support people with dementia and support carers in their own solidarity



Dementia

The Ethical Dilemmas of Carers

- Making decisions - first assess mental capacity
- The judgement of what is in a person's
‘Best Interests’
- Questions of Restraint
 - what is meant by the terms
‘justifiable’ & ‘proportionate’
(Mental Capacity Act)

These are not just issues for the professionals
Carers need our support,
and appropriate educational resources



Trust

*“To be cared for by others requires **trust in the carer**. It requires recognition of the carer as caring and of the importance of **human community**”*

- consultation respondent

We recommended that

**Unless there is evidence to the contrary,
there should be a
presumption of trust in carers**



Confidentiality

“Sometimes families do not understand when you explain about confidentiality, and they are frustrated not to be involved in consultations”

- consultation respondent

- **We supported the position that confidential information should be disclosed only in the best interests of the person with dementia**
- **Best interests are often interpreted too narrowly; carers will generally need the same level of information as any other member of the caring team**



Support for making decisions

We recommended that

The Codes of Practice on mental capacity
should be amended to emphasise

good communication

supportive relationships

joint decision making




Considering carers' own interests

- Carers' needs are important quite apart from any benefit to the person with dementia

Even though their relationship may be of fundamental importance to both of them


- It may be difficult for carers to genuinely consider their own interests and needs

Professionals should encourage carers to consider their own needs and interests when they are making difficult decisions

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The important issues for people with dementia and carers

- A person with dementia should be respected as an equally valuable person
- More support is needed in dealing with daily ethical dilemmas in dementia
- Carers should be treated as ‘partners in care’
- There are implications both for how care is shared, and how information is shared
- More dementia-specific guidance is needed under the mental capacity legislation




The messages for those providing services

- Is the person with dementia being treated as an individually valued human being?
- Carers need access to education and support
- Support the carers to make ethical decisions
- ‘Timely’ diagnosis – when it’s right for **this particular person**, their family and friends
- Flexible services – meeting the needs of **this particular person**, their family and friends

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The messages for those commissioning services

- Dementia is a **medical disorder**
- It is unacceptable to leave people without support - until a crisis occurs.
- Access to services should not be determined by **classifications** of care
- It should not matter whether the care is classed 'health' or 'social' – high quality is what counts
- The key issue here is **access**

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The implications for society as a whole

- Dementia needs to become an accepted, 'normalised' and visible part of our society
- We all have a role to play in tackling stigma and discrimination
- We need to make 'reasonable adjustments' for dementia, when providing services: in shops, cafes, leisure services etc
- We need more 'dementia friendly' buildings and environments



The Nuffield Council Report Further Information

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www.nuffieldbioethics.org/dementia