

Dementia: ethical issues

The needs of carers

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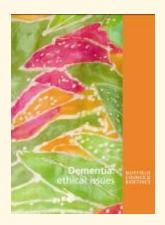
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Dementia: ethical issues Report of the Working Party

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







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 <u>same</u> level of information as any other member of the caring team

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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





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





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





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

Dementia: ethical issues

www.nuffieldbioethics.org/dementia

