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**An Ethical Framework to Support People with  
Dementia and their Carers**

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**NUFFIELD  
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BIOETHICS**



# Introduction

[www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)

# The Nuffield Council on Bioethics

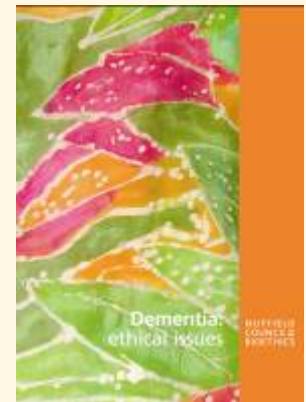
- Established in 1991
- Independent body that examines ethical questions raised by advances in biology and medicine
- Contributes to policy making and stimulates debate




# Dementia: ethical issues

## The report

- 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





# Our view

Those who support and care for people with dementia need more support in tackling the ethical problems they meet every day

We conclude there is a need for:

**Education** – to help respond to dilemmas

**Forums** – to share and receive support



# **Dementia: an ethical framework**

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# 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



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# 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

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# 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



# Ethical approaches to care

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# What is ethical care?

We conclude:

- 1. How things are done, will often be more important than the structure of services**
- 2. Professionals and care workers should treat families as ‘partners in care’**



# What is ethical care?

- Diagnosis
- Information, communication, signposting
- Ongoing care and support
- Acute hospital services
- End of life palliative care



# Dementia and society





# Combating stigma

- People with dementia may feel devalued and/or excluded from mainstream society
- Our ethical framework emphasises the importance of equality for people with dementia
- Information and awareness campaigns are only one part of the story – dementia must become an accepted, visible part of our society



# Promoting inclusion

People with dementia need to feel comfortable carrying on with their usual activities, for example:

- ✓ going to a club or out to lunch
- ✓ participating in church activities
- ✓ taking part in voluntary work
- ✓ involvement in dancing, art and music



# Dilemmas in care



# Overview

- Ethical dilemmas arise on a daily basis
- These are often stressful
- Those providing care need more support in tackling these dilemmas
- Guidelines are helpful, but not enough

We recommend

**Those involved in direct care of people with dementia should have access to ongoing education and support in ethical decision making**



# Assistive technologies

Concerns include:

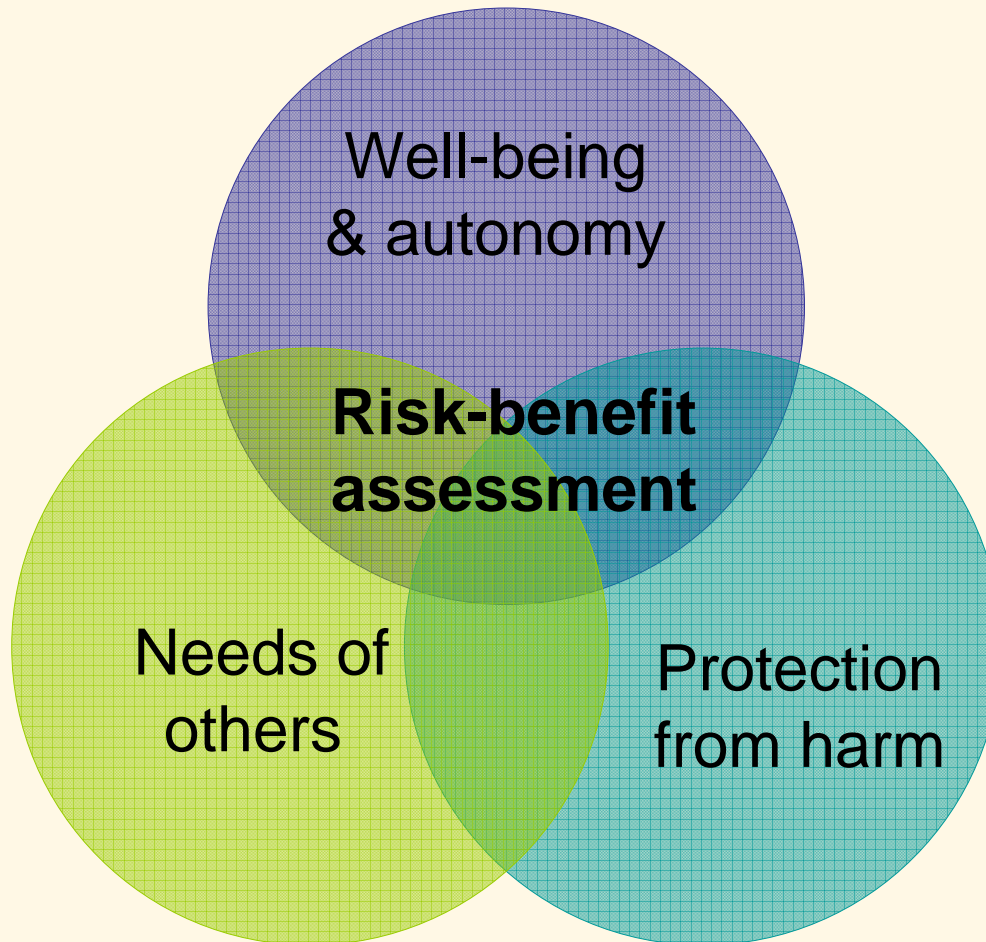
- Intrusion of privacy
- Stigma (particularly tracking devices)
- Risk of reduced human contact

We conclude


**The use of assistive technology should be considered on a case by case basis, taking into account:**

- the person's own views about privacy
- the likely actual benefit
- impact on the carers' interests
- dangers of loss of human contact

# Balancing freedom and risk



We recommend  
**'Risk  
assessments'**  
should be  
replaced  
by **'risk-benefit  
assessments'**



# Abuse

A recent survey of UK carers for people with dementia found that in the previous 3 months:

- 1% had hit or physically hurt the person
- 33% reported behaviours categorised as psychological abuse

Abuse and neglect may be the result of stress, ill-health or exhaustion of the carer

We conclude

**We emphasise the need both to act to protect the person with dementia and to support their carer where the person with dementia continues to benefit from their care**




# The needs of carers





# Joint support in dementia

- In England: **476,000 unpaid carers** of people with dementia
- In Europe: 50% of carers of people with **late** stage dementia spend over **ten hours** each day providing care
- **Professional support should have a wide focus, helping carers to support the person with dementia**



# 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



# Trust

We conclude

**Unless there is evidence to the contrary, there should be a presumption of trust in carers, by health and social care professionals, and by care workers**



# Confidentiality

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

- consultation respondent

- **We support 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**



# 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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# Conclusions

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**Thank you**

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