




# **Ethical issues in dementia care and diagnosis**

Professor Jonathan Montgomery

Chair

Nuffield Council on Bioethics



# The Nuffield Council on Bioethics

- Independent body that examines ethical questions raised by advances in biology and medicine
- Contributes to policy making and stimulates debate
- 3 UK based funders - Wellcome Trust, Medical Research Council and the Nuffield Foundation

## 2007 Working Party on dementia

- Members with expertise in ethics, front line care for people with dementia, law, old age psychiatry and neuroscience
- Evidence gathering involving deliberative workshop and public consultation, including an adapted version for people with dementia
- Draft report peer-reviewed by nine reviewers

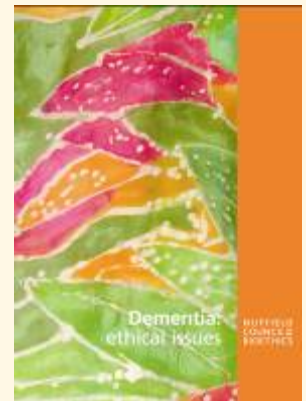
# Dementia: ethical issues

## 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

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




**NUFFIELD  
COUNCIL ON  
BIOETHICS**



# An ethical framework – six components

1. A '**case-based**' approach to ethical decisions
2. A belief about the **nature of dementia**:  
Dementia arises as a result of a brain disorder, and is harmful to the individual.
3. A belief about **quality of life with dementia**:  
With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.
4. Promoting the interests of the person with dementia and those who care for them - including their **autonomy** and **well being**
5. Acting in accordance with **solidarity**
6. Recognising the **personhood** of the person with dementia



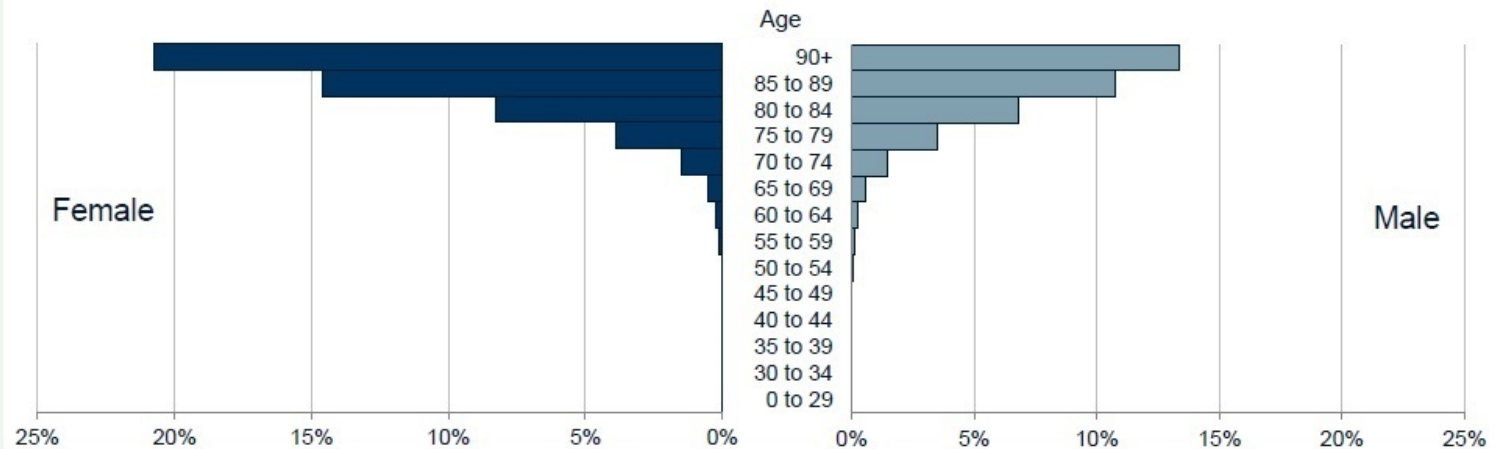
# Diagnosis in the UK

- Historically diagnosis rates have been low
- Alzheimer's society: less than half of people living with dementia in the UK have a diagnosis
- Big disparities within and between regions
  - 48% in England, 43,4% in Wales, 64,8% in Northern Ireland
- Efforts to increase rates sometimes controversial – e.g. 2014 *Dementia Identification Scheme*

# Increasing the diagnosis rate

New dementia quality and outcomes framework (QOF): 97 per cent of patients with a recorded diagnosis of dementia were accounted for by those aged 65 or over in December 2015. For those aged 65 and over diagnosed dementia prevalence was 4,245 per 100,000.


Recorded dementia prevalence, per cent of registered GP patients, England, by age group and gender, December 2015





# Recent UK initiatives

- **‘Join dementia research’** – joint initiative by the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society
- Alzheimer's Society **Dementia Friends** initiative “learning more about dementia and the small ways you can help”
- **Prime Minister's challenge on dementia 2020**
- **Joint declaration on post-diagnostic dementia care and support – signatories** across government, health, social care and the third sector



# Benefits of early diagnosis

- Prevailing view: diagnosis should be made as early as possible
- Benefits of early diagnosis include:
  - **Relief of understanding** what's happening (both for the person with dementia and those close to him/her)
  - Opportunity of accessing **appropriate support** services (including welfare benefits)
  - Advantages of having **time to plan**
  - Value of **developing a trusting relationship** with professionals






## But no single answer

“Early diagnosis is so important – so that I am involved in planning my future.”

“I was told very early that I have dementia. It was too early. My life would have been much easier without knowing my diagnosis.”



# Potential problems with *early*

- Uncertainty of diagnosis
- Wrong or premature diagnosis may cause unnecessary distress, worry and practical difficulties

“for conveying a diagnosis to be helpful and appropriate, it must be **timely**, with benefits balanced against risks. Where a person stands to be distressed to the point where no benefit can be derived, then even an early diagnosis is perhaps not a timely one.”

*Alzheimer's Society, responding to the Council's consultation*



# Other considerations

- **How:** The *way* in which a diagnosis is conveyed a key aspect of demonstrating respect for personhood and well-being of the person with dementia
- **To whom:** those responsible for communicating a diagnosis should actively encourage the person with dementia to share this information with their family, making clear that the diagnosis is of importance also to those providing informal care and support
- **What next?** Diagnosis should not be a one-off event but a *process*



# Wider context to diagnosis

- Prevalence of misunderstanding, stigma and shame – need to promote inclusion.
- Disadvantages in health care system, e.g. needs classed as ‘social’ – specific needs relating to symptoms of dementia not recognised
- Some cultural groups may be more hesitant in coming forward for diagnosis – need for a better understanding of why.



## Further information

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