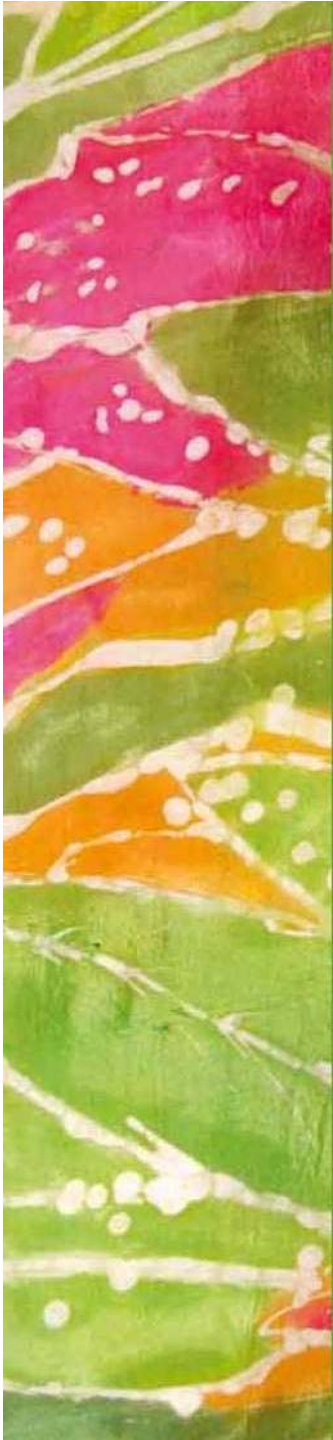


Dementia: ethical issues

The consultation process



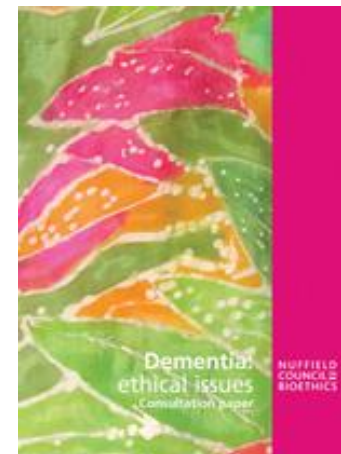
The Working Party

- Began work in November 2007
- Chair: Tony Hope, Professor of Medical Ethics, University of Oxford
- The group included members with expertise in
 - Medicine
 - Nursing
 - Neuroscience
 - Law
 - Sociology
 - Ethics
 - Representatives of people with dementia and carers

Public consultation

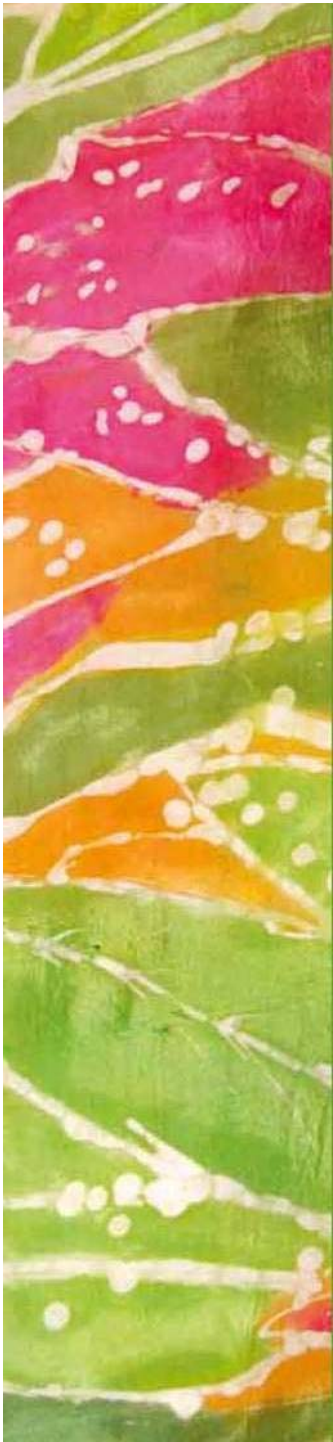
- Public consultation May-July 2008
- Consultation document
 - background information and questions
- Available:
 - Print copy
 - Online
 - Summary version

- Sent to over 1000 organisations and individuals
- Publicised on posters in care homes



Media coverage

BBC: Breakfast TV, local and national radio, online



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Page last updated at 23:08 GMT, Tuesday, 13 May 2008 00:08 UK

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Call for debate on dementia care

A debate is needed over the ethical dilemmas facing people caring for dementia patients, experts say.

The Nuffield Council on Bioethics wants to help advise carers and is launching a public consultation to gauge opinion on the tricky decisions made.



About 700,000 in the UK have dementia

It has posed a series of questions about the appropriateness of denying freedoms and the use of deception.

The council said it was acting as the number of people with dementia was set to rise with the ageing population.

About 700,000 people in the UK have the condition, but that figure is expected to double in the next 40 years.

Dementia is a degenerative condition which results in memory problems, mood changes and communication problems.

Among the questions being posed during the 12-week consultation are:

- Is it ever right to restrain a person to reduce the risks of wandering?
- Is it ever right to deceive by disguising medication in food?
- Should people with dementia be involved in research if they are no longer able to choose for themselves whether or not to participate?

“ It is not about making rules or saying what is wrong ”

Dr Rhona Knight, of the Nuffield Council on Bioethics

▶ 'I just want to protect him'

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- ▶ 'I just want to protect him' 14 May 08 | Health
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- ▶ Call for improved dementia care 03 Jul 07 | Health
- ▶ 1.7m 'will have dementia by 2051' 27 Feb 07 | Health

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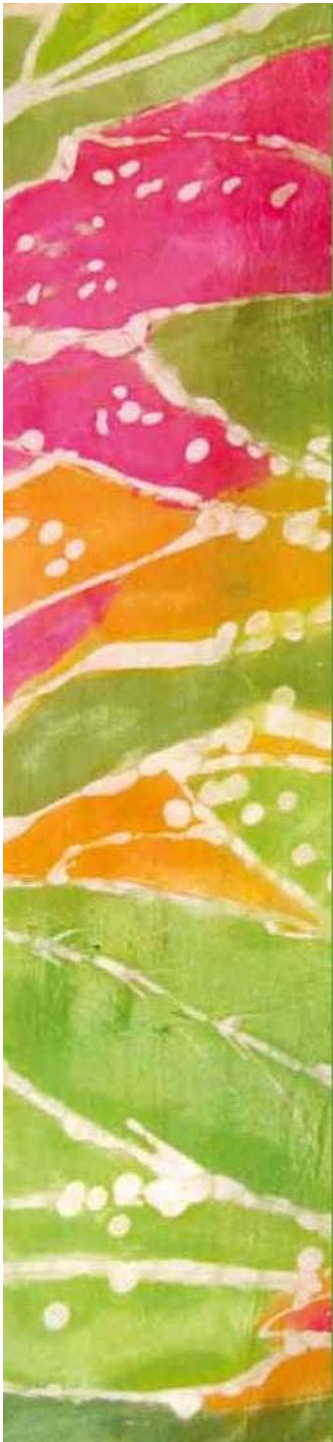
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Response to consultation

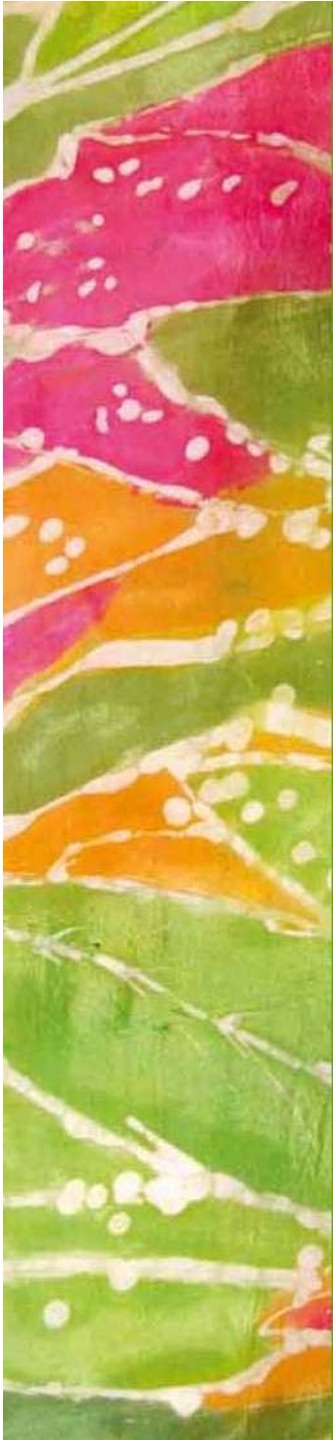
- 200 responses = over 1500 pages
 - 70% from individuals
 - 23% from organisations
 - 7% from organisations that arranged events
- From people with direct experience of dementia to eminent scientists & lawyers





'Fact finding' meetings

- June 08
 - Meetings with members of Bradford Dementia Group
- July 08
 - Meeting with people working at the 'front line' of dementia
 - nurse, GP, social worker, care home manager, unpaid carer, lawyer, person with dementia
- September / October 08
 - Visits
 - Vale House, Oxford
 - Alzheimer Café, Farnborough



Deliberative workshop

- A first for the Council
- One-day deliberative workshop
 - 50 members of the public
 - Held in Birmingham
 - Participants recruited and paid
 - Selected to be broadly representative
 - Received background information
 - Discussed ethical problems in groups
 - Professional facilitators



MEET PHYLLIS AND SANDRA

- Phyllis is 79 years old and has had dementia for 3 years
- She lives with her daughter Sandra and her family
- Phyllis is becoming more confused, and is less able to do things for herself
- Phyllis recently had a fall while in the bathroom in the family home and fractured her wrist
- Sandra is worried about letting Phyllis go to the toilet by herself and thinks she should be accompanied
- However, when Sandra has gone into the bathroom with her, Phyllis has become very upset



MEET TINA

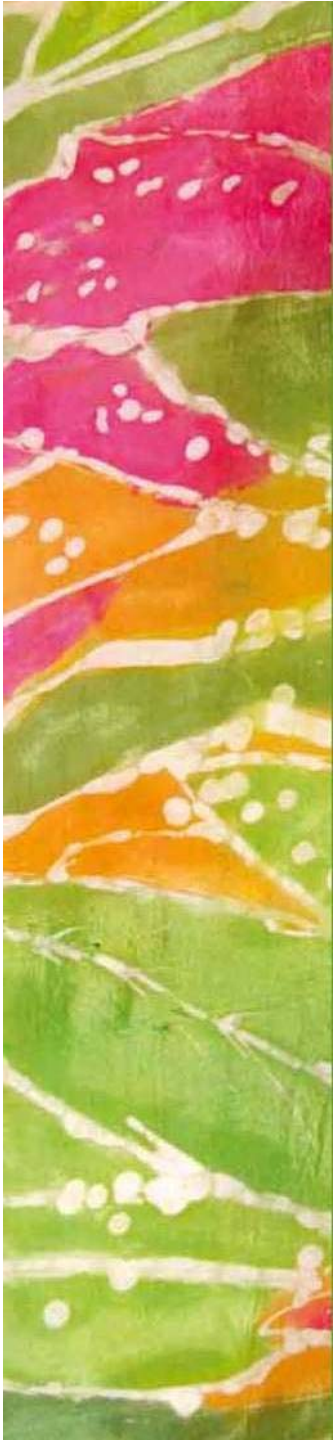
- Tina is 67 years old. She's had Alzheimer's disease for 8 years and now has severe dementia
- When first diagnosed with Alzheimer's disease, Tina told her family that she would not value life with dementia
- She said that in the future, if she could not make decisions for herself, she would not want medical treatment which would prolong her life
- Now, Tina appears very contented in her care home, reading random pages from a detective story, drawing the same picture over and over, and eating her favourite food
- Tina has been diagnosed with early stage lung cancer which will eventually kill her, but which is treatable
- Doctors have asked her family whether they want Tina to receive medical treatment for the lung cancer



MEET CLARISSA AND TERRY

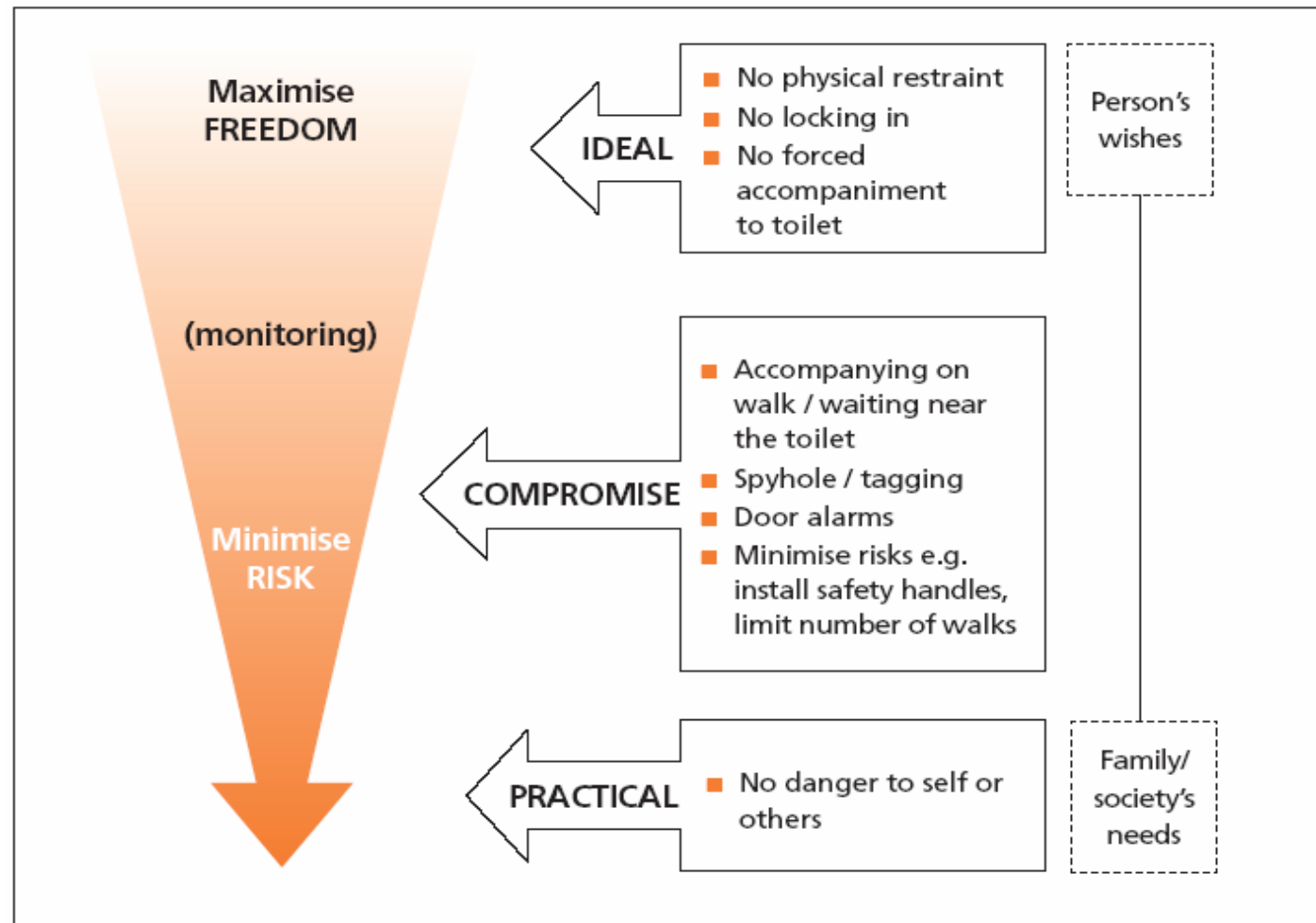
- Clarissa and Terry are both in their 70s
- Clarissa has been caring for Terry for the last 5 years
- Terry's health has never been as good as Clarissa's as his lungs were damaged through TB when he was a young man
- As he has got older, he has found it increasingly difficult to move around and do things as he easily gets out of breath
- In the last year, Terry has also been suffering from dementia, following a stroke
- Clarissa was providing full time care to Terry but has recently had a fall and needed a hip and knee replacement
- An older lady herself, she is increasingly struggling to look after Terry and has found the last year really difficult, as Terry's dementia means he needs even more support
- Social services have been around and believe that the couple are not coping in their current situation

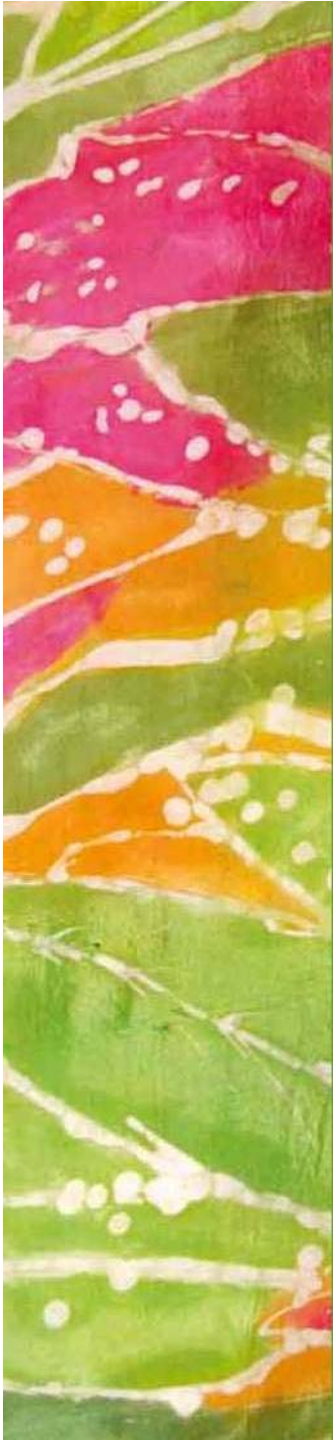




Report of workshop

- Quoted throughout main report
- Understanding of how people tackle ethical problems





Evaluation of workshop

- Evaluation questionnaire
 - Working Party members
 - Council members
- Value in providing credibility
- Demonstrated a wide consultation process
- Scepticism about how much was gained
- Concern whether the cost was justified
- Future consultations will be designed on a case-by-case basis



Consideration of all consultation activities

- One-day meeting of Working Party in Sept 08 devoted to discussing consultation outcomes
- Approach taken to the report grew out of this discussion
- Our ethical framework recommends a case-based approach where you start with the issues, consider the ethical principles, and compare with other similar situations – and this is exactly what the WP did for the report itself

Dementia: ethical issues

The report

Published October 2009

Conclusions and recommendations:

- Key themes
 - Ethical approaches to dementia care
 - Tackling dilemmas in day-to-day care
 - Decision making
 - Stigma and inclusion
 - Recognising the needs of family carers
 - Research priorities and participation



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