

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Nancy McAdam

The experience of dementia

The impact of dementia

Q1 In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most?

- Being unable to drive – I live in a remote rural area
- Living alone – my social contact has been reduced by the dementia and not being able to drive – isolation
- My 4 children have been worried about me – they have had to take on financial, legal and practical responsibilities for me much sooner than expected
- I am lucky that I am financially secure, I have good neighbours, my family are very supportive even although they live 200 miles away-these things are important
- When you get a diagnosis your life goes on hold until you come to terms with your diagnosis – so you need TIME and emotional support. But then you need information and direction to sorting out legal and financial matters

Q2 What difference (if any) does a person's religion, culture or family background make?

- In my family we have talked about my dementia openly. This has been important to me.
- I do not have a religious faith but spirituality is very important to me and I find peace and acceptance through nature.
- My personality is such that I try to get on with whatever life throws at you.

Diagnosis

Q3 When do you think a diagnosis of dementia should be made?

- **As Soon As!!!!** – Early diagnosis is so important – so that I am involved in planning my future

Person-centred care

Q4 Is the idea of person-centred care helpful? If so, in what way?

- **YES**
- The person has to be at the centre of services –they should be the focus – meeting their needs

Personal identity

Q5 Do you think that dementia can change people so much that they actually stop being ‘themselves’?

- **NO**
- Everybody changes over time – this is just natural, it’s part of life.
- Even when a person appears to no-longer ‘be’ the person they once were, they are still in there –
- see the whole person not just what is in front of you!

How society sees dementia

Stigma

Q6 In your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?

- Slower, dim-witted, unintelligent
- We need a bit more time to think and work things out
- Involving **real** people with dementia in media projects (not soaps) can educate the public – to see the real person and their lives

Q7 Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?

- **YES**

- Because we cannot drive we really need support with transport so that we can stay involved in community life
- I need opportunities to join in with everyone else but I also need the chance to meet socially with others like me (with dementia)

The government's duty to support people with dementia

Q8 What duties do you think the government owes towards people with dementia and their families, and why?

- I think that the government should help people with dementia
- Voluntary agencies are important in providing services, information and support

Q10 What do you think family or friends should do if they are worried about the decisions a person with dementia is making?

- Sit down and talk about it with the person with dementia. And if they are forgetful then write it down

Advance directives

Q11 Should people be encouraged to write advance directives? How should they be used?

- **YES** – I've done mine
- To inform any future decisions about that person once they can no-longer participate

Welfare attorneys

Q12 What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

- Everyone should try to work out what the person with dementia would have wanted.
- I would give more weight to my 2 daughters acting as welfare attorneys because they know me.

Dilemmas in care

Truth-telling

Q13 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

- Possibly – if for example someone forgets their husband has died then it could be hurtful to hear the news over and over as if for the first time.
- However, it would not be right to tell a complete lie – to say that he'll be here in a minute – so staff need to be skilled in managing situations through distraction and kindness

Freedom of action

Q14 Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?

- Individual freedoms are important, but if because of the dementia someone is creating a hazard or is a significant danger to themselves or others then society needs to intervene

Restraint

Q15 Should any forms of restraint be allowed? If so, when?

- Restraint is only appropriate as a last resort and should be done with as much care and dignity as possible.
- Staff levels and training needs to be such that they intervene before a situation escalates

New technologies

Q16 Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?

- New technology should be used to assist anyone with dementia living independently for as long as they can

Research

Research priorities

Q19 What should research into dementia be trying to achieve? On what basis should funding be allocated?

- Cure and treatments
- High priority