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.

(Please answer as many or as few as you please)

**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?

Q1. Dementia has a profound impact on the person with the illness, their family and the wider society. The person suffering with dementia experiences a very slow loss of attributes that make individuals human. The disease chips away at their personality, their skills and their judgments. For the families of dementia suffers it can be a living hell. Wider society is closed off to the illness and then when it strikes a family the results for all concerned is devastating. The support needed is at the outset of the illness the person with the illness can feel they are going mad but also those closest to them have similar feelings. However the care I would like to see with a dementia support centre in every locality (like the family centers for early years). Everyone concerned needs accurate information an ongoing support., it is a long journey!

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

Q2. Yes religion, culture and family background have an impact. Firstly religion there can be stigmas attached to the illness and residential care this can also apply to culture. A person’s family background also has an impact because early experiences which can be damaging can become traumatic for those concerned.
Diagnosis

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

Q3 Whilst I understand diagnosis is difficult in the early stages I feel it is vital in terms of coming to terms and preparing for the future. Even in the early stages of the illness the effects on the person with dementia and their family can be profound.

Person-centred care

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

Q4 Person-centered care is at the heart of all care and we must not lose sight of that, however as a carer I feel my needs or feelings were not taken into consideration.
Personal identity

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

Q5 Yes dementia changes people so much they do stop being themselves. As the disease takes hold some sufferers become walking dead. They appear to be under a great deal of stress and fear due to their confusion. I have heard people who works with dementia say" they are Ok in their own little world". From my own observations people with dementia are very anxious for a lot of the time.

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?

Q6. Society perceives dementia as going loopy or madness. There is a great stigma against mental illness in our society and dementia is also regarded as a weakness. In terms of support it does not get the attention like cancer. This may be because it is generally an illness of the old and in our society the old are not valued. We need more information on dementia in main stream culture and in the media. Persons with the disease are everywhere in our cities and shopping areas, alone confused and not coping. I never use to tune into these vulnerable people until it happened to my mum. Those who are in residential care are locked away, no one wants to know.
Q7. Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?

Q7. Yes maybe by having centres in the heart of every community including getting school children to get involved and others from the wider community. I believe we should get this illness out of the closet!

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?

Q8. Yes I feel it is the government’s duty to support people with dementia because these people have paid their taxes, been valued members of society and I believe we can only judge our society by how we treat our most vulnerable. Caring is part of a civilised society.
Making decisions

The law on making decisions

Q9 How do you think a person’s past wishes and feelings should be balanced with their current wishes and feelings, if these seem quite different? Is the past or the present more important?

Q9 and Q10. These questions are for the individuals and their families to decide. It maybe useful if every family had a dementia support worker who was a key person giving them information and support with these difficult decisions.

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

Q.11 Should people be encouraged to write advance directives? How should they be used?

Q.11. Yes people should be encouraged to write advanced directives but some individuals (like my mum) would not do this as they are in total denial about their illness.

Welfare attorneys

Q.12 What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

Q.12. A third party may be useful in these situations, a review meeting could be used with independent people who are knowledgeable about the illness.
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?

Q13. Sometimes it may be appropriate to not tell the truth to spare the person grief. This information could be recorded and the reasons given.

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?

Q14. This is very difficult due to the fundamental nature of the illness. Again this needs to be taken on an individual basis. Wider society has also to be considered e.g. my mum very nearly caused accidents.
Restraint

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

Q.15. Restraint should always be the last resort but there are circumstances when it may be required due to aggressive behavior. Drugs should be used in similar circumstances but with regular reviews.

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?

Q.16. New technologies will become more useful but should not be used instead of care and support or as a cheap option.
Carers

The impact of being a carer

Q.17 How can professionals (such as doctors and social workers) help if a carer's own needs are very different from the needs of the person for whom they care?

Q.17. There needs to be a balance between the person being cared for and the carer. As a carer I feel my needs were not being met.

Confidentiality

Q.18 Is it too difficult for family carers to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?

Q.18. I have not found a problem in getting information. I have found that some doctors have not read my mum's notes and did not know she had dementia or they talked to her about her illness without considering her feelings.

Please feel free to respond to as many, or as few, questions as you wish
Research

Research priorities

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

Q19. More understanding, treatments and new ways of caring as part of society.

Involvement in research

Q20 What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?

Q20. I feel that people with dementia who maybe cannot make their own decisions should be involved with research by asking the families permission. The benefits are too valuable to miss.
Other issues

Q.21 Are there any other ethical issues relating to dementia that we should consider?