

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.

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What is dementia and how is it experienced?

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 by people with dementia and those caring for them?

The feeling of being out of control not knowing why your mind is deceiving you. The fact that many people continue to live with the onset of dementia without any medical help or guidance. Seeking help for medical issues to do with the mind was previously taboo. The fact that individuals are quite scared and try to hide the symptoms for as long as they can and usually a partner/ spouse or close family member help make things appear normal.

Support is made available but the constraints of health & safety requirements mean that the family carers or spouse or partners have to do a lot of the tasks. When you love someone you will do whatever is necessary but this can be an enormous strain and ultimately destroy the carer's health. Help is only available on predetermined packages an hours slot to help with dressing and feeding. Outside of these hours the carer can be at their wits end as the need for help can happen at any time of the day and does not fit neatly into any package.

There needs to be a screening programme to identify those people who are most at risk of getting Dementia. In this report it clearly states that there is a link with under active thyroid and Alzheimer's. More could be done to help slow down dementia. More research needs to be done to help us understand the illness and what proactive things can be put in place to help people lead a normal life as long as possible.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

The fact that old people when they can no longer care for themselves are placed in residential care as they would be at risk if they returned to their homes. They lose all their civil rights, as they are virtual prisoners. Often hospitals are declaring people medically fit which means that can do no more for the patient and are shipped out at an alarming rate and placed in inappropriate care homes. A higher ratio of staff is needed to care for these people. Also a more highly trained workforce who understand how

dementia progresses and staff who are able to empathise and give individuals the care and dignity they require.

I have recently observed several individuals within a residential home walking around distressed and confused looking for their husband or even their Mum and Dad and no-one attempted to help or reassure them. I was constantly at the home for three weeks as my father was dying and bedridden as staff could only attend to him on a two hourly basis. Nursing care which PCT awarded the extra 100 pounds was very little different than residential care.

Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

From my experience people think once you get to a certain age then dementia has to be expected. The ethos now is to help people to live longer but there is no point if the quality of life is so poor that it is not living but just existing. With an aging population increasing more needs to be done to ensure that they live a life which has quality. More services need to be provided to help older people enjoy the time they have left.

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

People's individuality requirements should also be considered as everyone has a different cultural background and beliefs and these should be valued and where possible accommodated. Illness has no boundaries!!!

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

A more proactive approach where people are given an MOT for health at say age 50 which would help alert the medical profession and individuals to potential health issues which may be commencing. It would also identify people which maybe starting with symptoms of some form of dementia which could be slowed down by drugs and give people extra time to live normal lives.

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

A diagnosis should be given ASAP so that medication can be given which may slow down the onset of dementia but also the families and the patient can look at the differing treatments and assess which one would be more appropriate.

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Yes we do, we need to communicate to everybody that dementia is an illness that anyone can get and should be treated with care and sensitivity. People need to be educated so that they understand better what the illness is and how it can be best treated. Better support needs to be available to carers as often they feel lonely and isolated. Often the diagnosis is well into the illness as carers try to hide and compensate for behaviour of the effected person. These carers need to be encouraged to seek medical help at an earlier stage. Help must be available and easy to request.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

Mental illness has always been regarded as a stigma by society so people keep quiet as they are ashamed to acknowledge that there is a problem.

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

Every effort should be made to allow the person to remain in the family home with appropriate help and respite care.

Person-centred care and personal identity

Q10 Is the idea of *person-centred care* helpful, and if so, in what way?

Yes as it is looking at the individual and what they need based on their values and cultural background.

Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?

Yes over time it does. The person usually tries to cover up memory losses and then withdraws from conversations and lets the world go by rather than joining in as they feel unable because of the dementia taking control of their minds. They become frightened as they do not understand what is happening to them.

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

Radical mood changes and behaviour changes in anyone in a family can cause arguments , ill feeling even break ups so dementia will cause all of these and more issues.

Q13 When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

Families should always remember what the individual values and wishes were before the illness so that this can be given a high weighting in deciding treatment. More and more I believe people should write down their wishes in a living will so that if they are incapacitated the family know of their wishes making decisions about treatment easier.

Q14 What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

Where a person has no family an ethical judgement will have to be made. Treating someone with medication which keeps them alive but where they cannot take part in any meaningful way could be judged to be cruel and at this point maybe the pathway where medicine is withdrawn accept to make the person more comfortable should be the humane approach. This happened with my Dad and he got the best care at this point.

Q15 How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

As above.

Q16 What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

They should go to mediation panel made up of people who understand dementia and who have been through the same sort of things with their family.

Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

This is a good idea as the medical profession, legal profession and families would be aware of their wishes which would help everyone to respect the wishes previously stated and should be honoured.

Q18 What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

Research should be looking to identify the onset of dementia and look at how to slow down the onset of it.

Q30 What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

People who lack capacity to give consent to take part in research should not be used, but families may wish to allow it if it gives hope to other potential sufferers.

Q31 Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research which you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

Other issues

Q32 Are there any other ethical issues relating to dementia that we should consider?

Residential homes do not have the training or enough staff to resident's ratio to give the Care needed. All care staff should be trained up about dementia and know how to deal with individual people. From my experience all residents are kept in a lounge area so that they can be watched. Very little activities go on and the ones with dementia seem worried and anxious all the time and roam around the building looking lost.