

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?

In my opinion dementia can be devastating for families. There is not enough support or signposting available. Carers know so much about their loved ones, yet they are treated sometimes with contempt by nursing staff and are sometimes made to feel as if they are a nuisance.

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

Many people who are not familiar with dementia are afraid of the unknown. People with dementia can have periods of time when they appear to others to be very frightening. What we have to understand is that the patient themselves is confused and what is classed as challenging behaviour is in fact their defence mechanism.

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 personal experience it is quite rare to see an ethnic person with dementia. Different cultures tend to care for their own and the tendency then is to keep their loved ones at home for as long as possible.

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

There definitely needs to be an awareness of the different cultures and the individual requirements, ie religion, food, communication.

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?

I understand in Australia there have been trials of injections into the brain stem with significant outcomes. Other than that I am not aware of any other developments. I know there is a great deal of research going on with carers, health etc and there are always reports of some kind or other

being published. Again a personal comment – there is too much emphasis on words and not enough on actual care of the patients with this illness.

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?

I do firmly believe that diagnosis should be given early and at the same time support put in place for the individual and the family. A diagnosis of this type cannot be made without support and people have to be advised of the final outcome of the illness, but also be encouraged to live a full and as normal a life as possible.

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?

Dementia was always really a taboo subject, but I think this country has now woken up to the fact, that if we do not address the very serious issue of an older population, we will be in trouble.

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

Many people are, for want of a better word, ashamed to admit they have a family member with dementia. We need to educate people that it is an illness of the mind, and that there is no shame in someone having dementia. We need become a more tolerant society and accept that it is simply an illness that needs compassion.

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

I firmly believe that communities need to embrace people with dementia. Six Alzheimer's cafes in South Staffordshire have been established recently and are a perfect example of how carers, families and their loved ones with the illness, can mix in a social atmosphere, network with others in exactly the same situation. Although no two people are ever the same in the path their illness takes, knowing others are in a similar situation does I believe help.

Person-centred care and personal identity

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

Person-centred care can be extremely helpful, if the time and effort is put into making it work. Carers/Nurses have to take the time to learn as much as possible about the patient and work on all the elements that can stimulate their senses.

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

The change in identity can be enormous and the mood swings that accompany the illness also can be varied. In the final stages where the patient becomes very passive, staff must continue to treat the person as a human being, not talk about them but talk too them and involve them in things that are happening around 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?

If behaviour becomes aggressive, it is bound to have an impact on relationships. It is easy to say remember the person as they were before, but when someone is lashing out at you, it is simply seen as challenging and aggressive. We have to remember, the person is going through enormous change in their lives and things which to us seem run-of-the-mill to the patient can be frustrating and difficult to deal with.

Making decisions

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?

This is a really difficult question to answer but I do think if the person expressly requested things when they had capacity, then those wishes should be adhered to.

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

I am not sure what is meant by this question if you lack capacity you lack capacity.

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

At the time of diagnosis, families and their loved ones should discuss things in depth.

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?

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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?

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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?

I personally think the Acts have made it a little easier, by dotting the 'I's' and crossing the 'T's

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

I think there are varying ways of dealing with questions, not with a lie but with a 'bending of the truth'.

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

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Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

If a person is really agitated and aggressive, then the nursing staff should have the final decision regarding restraint. From personal experience I know that my loved one was put into a straight jacket and a semi padded cell, which to me was horrendous. However, it was bonfire night and he really thought he was back in the Army and in a War Zone – he could have hurt others including patients, nurses and himself. I had to step back and understand the situation, rather than have a knee jerk reaction to what I saw.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

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Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

There are many people who have issues with these new technologies, as they say it is removing people's privacy. I would rather my loved one have been tagged rather than lost and roaming the streets.

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

If a person has dementia, they are still a human being and they have the same rights as any other family in the country. The state has to treat them with respect and care for them – there should be absolutely no boundary.

The needs of carers

Q25 How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

Again, from personal experience, I have had conflicts as my loved one's dementia has progressed. However, I do have a brain that works perfectly well and I take great exception when a young carer, who does not know my loved one as well as I do, tries to undermine the care I am giving.

I also think carers have the right to ask about medication which is being used and why tranquillisers are removed at a time when the person is probably very depressed.

Q26 What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

My experience is that health and social care professionals DO NOT help resolve conflicts of interests in these situations, they always take the easy route out. Because I am only a sister of a brother with Alzheimer's I do not have any rights to contest things because I am not next of kin. But as a sister, he is my bloodline, and if I see him with bruises and sores, I feel entitled to ask questions and get answers from a care home.

Q27 In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a *couple* (or of a household), instead of concentrating solely on the interests and needs of the individual?

I suppose if the wife of the person with dementia is suffering ill health because of the commitment to her loved one they health or social care need to intervene.

Q28 From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

All information should be shared with the family carers. This person is still their loved one and as such they should be given every single bit of information necessary.

Research

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

The future statistics on Dementia are absolutely frightening. Funding to investigate this disease should be given as a priority. We as a country are in danger of reaching a crisis point, with people living longer and the care homes getting fuller.

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?

Again a difficult question, but I do think research is needed into certain areas of dementia:

I am told by his GP that my brother who has Alzheimer's does not feel pain. Why then does his face contort as though he is in pain? He cannot speak, walk, or talk – so how do we know what he is feeling.

I would like research into how much he can hear?

I would like research into just how bad his eyes are – not impressed when he is wearing someone else's glasses – what can he actually see?

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?

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Other issues

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

I think we should seriously be considering the type of training given to care staff in nursing homes, hospital wards and also to carers that are paid to go into homes and care for people with dementia.

No-one deserves to die without an identity and without dignity. I have witnessed too many people humiliated in hospital wards and nursing homes; people who cannot walk, or talk and who are spoken about as if they are not there.

CARE is the word that I feel is missing from all aspects of nursing people with dementia. TIME is essential to spend with people, listen to them, talk to them, cajole them when they are difficult, understand them when they become fractious, reminisce with them, for after all they did not ask for the disease – treat them with sensitivity. after all who knows one day it could be one of us in exactly the same situation.

