

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 aspect of dementia that has the greatest impact is the loss of who the individual really is. Aspects of character remain, but often the person becomes unrecognisable to the loved one. The support needed is tactful, tender loving care and to be kept safe, secure, well fed and warm.

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

Some people with dementia exhibit violent tendencies. This can be difficult to manage in a home setting and sometimes a care home setting is more beneficial, where staff have experience with these sorts of difficulties.

**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?**

It is possible that different ethnic minorities might look after their elderly in a more family orientated environment and therefore make the care of a loved one easier. People of different religions might have different ways of dealing with dementia in their community and resent outside help.

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

Different religious practices must be taken into consideration when dealing with multi-cultural settings. Empathy with food preferences, clothing differences, the need to pray several times a day and various other things are helpful.

**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 have heard of a new drug that arrests the development of dementia for a time. This is of considerable use in lengthening the quality of life of people with dementia. However, there seems to be a post code lottery

concerning it being prescribed. If everyone who needed it could have it, that would indeed be a step forward.

**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?**

The diagnosis should be communicated to the individual as soon as possible, I think, so that life can be lived to the full while it is possible. Not telling an individual can lead to deep suspicion and the losing of trust with friends, relations, and health professionals

**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?**

I think society perceives dementia as something that happens to other people and leads to slightly odd behaviour. I don't think the full import of the condition is understood by most people, unless they have experienced it with a relative or friend first hand.

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

There is a huge stigma connected to any mental illness or difficulty. This is mainly because it is largely invisible to the general public. A broken leg is obvious, dementia can come on very slowly and be difficult to detect in the early stages. People are reluctant to admit they have a problem, because it is embarrassing to admit that you can't control your actions or memory as much as before.

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

People with dementia should be included in everyday life in the community. Properly trained staff can run day centres for people to visit once or twice a week, for a social interaction and maybe lunch, to give the carer a break. It is important for people in the community to have contact with people who have dementia to learn how to deal with it.

### **Person-centred care and personal identity**

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

It is important to treat each person with dementia individually and set up a care package with their needs in mind. No two people react the same or need the same things.

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

In my view people with dementia change in personality rather a lot. This in turn can bring to the fore childhood traits that haven't been seen for decades. Sometimes people become aggressive when they are usually passive and visa versa.

**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?**

It can be extremely difficult for a spouse to cope with changes in mood or behaviour when the person they knew before was the opposite of what is before them. This can lead to family feuds and isolation. Someone's values and wishes should always be respected both before and after dementia sets in.

### **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?**

All the family should be involved in any decision about the person with dementia's life. Their past and current wishes and values should be evaluated carefully and an agreement reached with the family, health professionals, and the spouse, that is most appropriate for the person concerned.

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

In this situation very tactful handling is required to avoid unnecessary upset on either side. A sympathetic approach is best involving the family, health care professionals and the person's spouse.

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

I think quality of life is of paramount importance rather than quantity, and would bear that in mind when life-sustaining treatment is discussed. As long as the person is relatively well, and enjoying life in their own way that is fine.

**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?**

I am not sufficiently equipped to answer this question.

**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?**

Advance directives should always be taken seriously, provided they are made while the person was of sound body and mind. No one should ever be coerced into signing anything while incapacitated.

**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 am not familiar with these acts of law. I do believe that people being cared for more in the community instead of in long stay hospitals, must be a step forward.

#### **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?**

It may be necessary to go along with what someone with dementia is saying to avoid conflict and confrontation and possible violence. I do not think it is a good idea to lie in order to get someone to co operate, and tender loving care should be the order of the day.

**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?**

I think in general people err too much on the side of caution when considering risks. It is every individual s right to take risk in life as long as supervision is available to avoid danger.

**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?**

No form of restraint is permissible. I think the law protects the right of the individual concerning possible restraint.

**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?**

All people who work with people with dementia should be highly trained. In house training should be supplied in care homes and with agencies concerned with the care of people with dementia.

**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?**

I have never heard of smart homes. Electronic tagging is not appropriate with people with dementia. It is useful to have some form of ID on an individual in case they should wander or get lost in some way. A wrist band with name, address and telephone number is ok or maybe a note kept in the back of a purse. This is so that Police and other services can return the person to the appropriate place in an emergency.

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

The state should make more facilities available to people with dementia and their families, including suitable care homes and day centres, with appropriately trained staff in them.

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?**

This is a very difficult problem. Respite for the carer is paramount. At the appropriate time a care home should be provided that will give the carer a week off occasionally, to rest and recuperate. If this happens regularly the person with dementia gets used to it, and even looks forward to a change as well.

**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?**

Social care professionals need to be very tactful when suggesting different strategies for dealing with a dementia case. It is never right to ride rough shod over the family and not consult them about things which are important. *It is better to avoid confrontation and be calm and sensible when discussing possible solutions to ongoing problems.*

**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?**

If the couple are aged (over 90 for example) a solution for both people might be more feasible. Also they may have been together for years and cannot bear to be parted. Sometimes a room in a care home can be set up for a couple to inhabit, or care at home organised to help everyone.

**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?**

Sometimes it is difficult to gauge how much information is needed in any given situation. I have found in my experience that enough information has been supplied, to make sensible decisions. It is difficult for any professional caregiver to decide how much information should be shared with families. This would depend on individual circumstances.

#### Research

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

Research should concentrate on slowing the dementia process down and detecting it at an early stage. Funding should be allocated as and where it is needed.

**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?**

I do not feel equipped to answer this question.

**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?**

I do not feel equipped to answer this question.

#### Other issues

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

None I can think of.