

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?

- Obtaining initial help when mysterious symptoms appear
- Obtaining diagnosis
- For young onset families, having the medical community generally appreciate that young onset dementia exists
- Obtaining help through the different stages of the condition, for both the person who has dementia, and their closest loved ones
- Being able to keep the person who has dementia at home for as long as is practically possible
- Impact: behaviours associated with dementia
- Impact: loss of family and friends once diagnosis is known
- Impact: loss of job – and maybe home – when family is young onset
- Impact: physical, mental and emotional effects on the carer

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

- I am unsure where ethics sits here, but my wife's care home has been reported for restraining her by using a lap belt for the chair to which she is confined. This was something that had been agreed between me, the home and the GP, for her safety. Sometimes misplaced ethical considerations can get in the way of good practice – most likely because the considerations are most regarded by those with no practical knowledge of the problems of the condition.
- However, of course, each case needs to be taken on its merit with all those involved discussing the pro's and con's

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?

- Yes they do, depending on the closeness of families through the different communities.
- Yes they have to be relevant because these are the people living with it and they need to tune what is done to the understanding of their community.
- This should not in the best of all worlds affect the care of the person with dementia

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

- If the culture of incoming people conflicts with the existing one, then the primary focus on care needs to be with the majority. The incoming cultures need, within themselves, to appreciate where they are now living.

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?

- It seems to a carer that the scientific community knows a minute amount about dementia and its causes, let alone anything that can be done to stop it occurring.
- Treatments and care packages for people with dementia are in general, patchy and dire.

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?

- This is not something that can be applied universally in my view
- I asked that the diagnosis not be given to my wife because I don't think she could have coped with it, and I could not have coped with her not coping with that.
- It took so long to get a diagnosis as my wife was a younger person that by the time it had been made, whether or not to tell her was a mite academic, anyway
- Case by case decision

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?

- Until a family is faced with a loved one who has dementia, they can never appreciate that it is not simply 'forgetting things'
- Society has very little knowledge of dementia, of the types of dementia, on the way dementia presents itself, on the effects on younger/older/geographically distant families
- How? By taking the stigma away, by having the public realise that the person with dementia is not 'in the land of the fairies' and that with time we can establish new forms of communication.
- Call dementia "cognitive cancer" or something with cancer in it, not matter whether it is clinically/scientifically correct. The public understands more of the seriousness of cancers and nobody jokes about it, unlike dementia, alas

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

- A great part. There is stigma with dementia whereas there is not with cancer.
- Stigma with dementia in some ways echoes stigma with HiV though dementia is more serious as it cannot be treated

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

- Totally dependent on the person and the stage they are at and the willingness

of the wider family .

- Totally dependent on what is meant by 'include people with dementia' as beyond a certain stage it is impractical
- Trying, without regard to circumstances, to include people, can be cruel in itself – both to the person concerned and their loved ones

Person-centred care and personal identity

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

- Care for someone with dementia HAS to be person-centred as the disease affects each person in a slightly different way and an appreciation of their specific condition, their medical history, their familial history all need to be considered.

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

- Depends on viewpoint and willingness/ ability to engage with the person:

For a spouse, although there may be considerable changes, the identity may appear to be absolutely the same. Spouses fool themselves to be able to carry on, and day to day, minute to minute attrition caused by the disease hides step changes.

- For an occasional visitor – whether or not a family member – there may be a massive change apparent
- A doctor may notice nothing at all as frequently a person with dementia has great capabilities for appearing their normal selves for a short period – up until a certain stage.

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?

- Big implications. For instance a relative may have promised, in all honesty and innocence, not to consider a care home.
- Once the condition worsens beyond a certain point, that promise might need to be reconsidered in the light of the needs and safety of the patient, and the health and safety of the carer
- Lying about things may need to become the norm in helping the sufferer and the carer to get through the day

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?

- I can speak only as a spouse of long term.
- Past wishes and values need to be balanced with love, and sometimes that love and caring needs to put past feelings and wishes to one side.

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

- I can speak only as a spouse of long term.
- In a loving relationship only the spouse is likely to know, though care needs to be taken of course

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

- I can speak only as a spouse of long term.

In a loving relationship only the spouse is likely to know, though care needs to be taken of course

- In my own case with my wife, I have asked for 'no resuscitation', also 'no influenza jabs'

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 can speak only as a spouse of long term.
- Unless the disagreement is truly major, the attorney if a spouse should hold sway, unless it is felt that they themselves are incapable of deciding.

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 be honoured
- Along with their Will and an LPA, all people should have an advance directive to safeguard their interests

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 have no views as I know them neither in detail nor in outline

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?

- Firstly, what is truth? The world of the person with dementia is not the world of someone outside. What the person who has dementia sees and interprets and understands is not necessarily ever what the onlooker sees, interprets, understands. There are no absolutes here.
- So truth is a moving feast.
- In my experience, beyond a certain stage of dementia, communication

between carer and cared for becomes an improvisation. When I leave my wife each time at her care home, I tell her I am 'going shopping'.

She appears to understand that this means I will return, whereas if I say "I am going now" she shows signs of distress.

- I asked that my wife not be told her diagnosis. The process of diagnosis took 8 years because nobody would believe that someone her age had dementia. By the time the diagnosis was firmly made, her condition was quite advanced. Had she asked me outright "what is wrong with me", I would have told her. She never did and we always settled on 'memory problems'.

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?

- Without input from a close family members, care staff will, to protect themselves, err on the side of caution.
- Sometimes the family member has to urge less caution, for the good of the subject. In my experience this works.

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?

- Yes of course. Anyone who thinks otherwise is either dotty or they have no experience of caring for someone with dementia.
- I can only speak in my wife's case, but she requires a waist belt in the chair she sits in for most of the day. Otherwise she would fall and damage herself.
- Bad interpretation of the law by people with training but no experience hinders.

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?

- Professionals in general need much wider appreciation of the entire area of dementia experience, practical and ethical.

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?

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

- The state taxes, re-taxes each person repeatedly through their lives. The state owes those people the provision of free care at the end of their lives.

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?

- The relationship is important:
 - o Spouse?
 - o Closeness of non marital relationship
 - o Proximity of family

A spouse very often has no choice but to go with their heart until circumstance and the needs of their loved one dictates otherwise. Outside intervention is unlikely to work even when the spouse is running themselves into the ground.

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?

- Firstly they need to understand the entire situation. They tend to compartmentalise their knowledge far too much

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?

- The needs and safety of the individual concerned need to be central. For a couple, the relationship, situation and outcome for both need to be taken into consideration as well. There will be situations where the spouse/partner will know more than the associated professionals in this respect.

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?

- The level of disclosure needs to be relative to the ability/willingness of the family carer to absorb information. In my own case I have always had to seek information; very little has been volunteered. If a spouse feels they need information, and asks for it, they should be given it, at once and in full.

A problem is the fragmentation of support. We had many doctors and professionals and there was little joining up of diagnosis and care.

Research

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

- Twin prongs:
 - #1 priority alleviation of the disease [because a cure is going to take too long for the current people who have dementia in the family] and better understanding of symptoms, familial effects, effect on young onset people, etc
 - #2 search for a cure

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?

- Involving how?
- If for observation, yes of course
- If for establishing care regimes, yes
- If for testing medication where efficacy has not been proved , then no- unless at some stage they themselves – being of sound mind- have requested it