

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.

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?

- Not recognizing nearest and dearest, and familiar surroundings.
- Aggressiveness not previously associated with person with dementia.
- Social Services to take more interest and to visit carer/person with dementia on a more regular basis to check that the situation is being dealt with in the best possible way for all concerned.
- Fuller explanation to be given to carer/family members of not only how dementia will affect the patient but also how it will impact on them.

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?

- Arthritic drug for dementia as tested in the States.
- More flexibility with regards to the testing of new drugs, especially the use of Aricept at the early stages of the diagnosis.

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?

- As early 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?

- Fully agree that we need to promote a better understanding.
- It needs to be explained that dementia cannot be transferred from one person to another.

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

- A large part.
- People are frightened; they do not know how to deal with this.

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

- No, because they cannot remember from one minute to next.

- Person-centred care and personal identity

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

- Yes, as the process comes on you.
- There is no time for person's wishes as the person you knew is absent through the effects of dementia. They are unable to recognize the carer/family or surroundings for more than a few seconds.
- Power of attorney - wishes listed but not necessarily understood as wishes were made before the onset of dementia.

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

- Completely.
- They become very selfish.
- They have no understanding/recognition of the person caring for them or any recognition of family members.
- They become aggressive because they do not know where they are as they become locked in a time warp, which can be as much as 25 years. For example, they remember their own mother who has been dead for 26 years, but do not remember/recognise their own husband/children.
- Makes it very difficult for a relationship between husband and wife.
- In my particular situation, I have now time for myself due to the selfishness of my wife who is suffering from dementia.

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?

- See response to Q11
- 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?

- As near as possible.

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

- Intervene owing to health and safety issue.
- Person could leave the environment they are in and within minutes not know how to get back to that environment, putting themselves and other people at risk. With dementia, a person can remember for a couple of

minutes and then forget everything that has gone before and therefore not understand what is currently happening.

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

- If a treatment is available and can be shown to improve the life of that person it should be tried.

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?

- Attorney should be given authority to look after the person's health and wealth care, providing that the person with dementia has agreed to the arrangements before the dementia has really taken hold.
- If the health worker/doctor disagrees with the carer then there should be a second opinion sought as to the welfare of the patient.

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?

- I am the carer of my wife; we had no time to consider advance directives and were given no advice on this during the slow onset of dementia. To my knowledge, the symptoms started to happen 5 years before the complete onset of dementia.

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 is better to tell the truth when dealing with dementia. If the person with dementia asks if their mother/father is dead, you must tell them. This applies to them asking about any other family member.

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?

- There is a need to minimize risk based on circumstances.
- There is a need to assess daily for risk and act accordingly.

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?

- Personal restraint should not be allowed.
- The only restraint should be locked doors to stop patients from going outside into the road/street without anyone in attendance.

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?

- Undoubtedly, specific training should be given. In some cases this should be delivered at the carers residence. A review should also be undertaken to assess whether additional training is required when there is a change in circumstances.

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?

- It is necessary to have some devices such as to give an indication when the patient leaves their bed. This is especially essential if they live in a house and are at risk from possibly falling down the stairs.
- Also essential to know if the patient leaves the property without the carers knowledge.

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

- Believe that the State should pay for care. Owing to the fact that we all enter this world with nothing, we work our lives for what we have got. Why should the burden be put on the other partner to supply all the care for the wife/husband.
- For the last eight years, I have only received attendance money for care which does not amount to very much when you are caring for the patient 24 hours a day/7 days the week.
- If you require a person to sit for an hour, it costs more money that what the person acting as the carer earned for an hour whilst they were working themselves. This is grossly unfair on the carer.
- Assessment should not come into it.
- 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?

- More free help from the professional bodies.

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?

- Keep carer and patient together.

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?

- See response to Q26

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?

- If a person has dementia, the family should be told exactly and everything that is necessary for them to work out the future of that family member. This must be told. No holding back on any point.
- In my experience I had to fight to get to know what was wrong with my wife.

Research

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

- Stabilise the dementia once it has been diagnosed, ie aricept should be given at the early stage and not mid stage.
- On the basis of need. Once the research has been undertaken, funding for those drugs should be given and not held back. There is no point in developing drugs if they are not used. Research undertaken is lost once that drug is refused to the patient.

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?

- If well enough to give consent themselves that is ok - consideration should be given to 'advance rights'.
- If advanced dementia and no 'advance rights' previously agreed, then members of the immediate family and health professionals must consultate to achieve what is the best recommendation/best way forward in the interest of the patient.

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?

- When research is completed in other countries but only undertaken on a limited trial, NICE appears to ignore these results as not having been clinically tested.

Other issues

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

- Who should decide who gives which the required drugs? Which health professional should issue the drugs to the patient concerned?
- I have often found that I can go to my Doctor who is unable to issue the required druge because they are issued any another NHS department. I have found myself going round in circles.
- One authority should issue the required drugs, ie GPs, as they are closest to the patient.