

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.

Question 1

ANSWER:

Aspects that have the greatest impact on the lives of their carers and families are: (1) the strain of coping with patients' difficult behaviour, especially tantrums and psychotic episodes, and the fact that these may be impossible to resolve and can continue for many hours; (2) the diversity of symptoms; (3) the lack of effective drugs and of someone qualified to administer them and who will agree to do so; (4) the unpredictable effects of drugs on the patient; (5) the lack of understanding on the part of medical professionals as to how difficult and stressful it is for relatives to live with someone with dementia, and the likely detrimental effects on their health. (1) The kind of support needed is practical help. A social worker should be allowed to help choose and arrange care at a suitable nursing home, rather than being limited to providing a supposed 'listening ear' by regular visits, which may become a source of difficulty, as they entail adjustments to the usual routine. (2) Direct observation of the patient's symptoms by a medical professional might be useful in encouraging the carer to place the patient in long-term care before it all gets too much for everyone (including the patient). For instance, if a medical professional would visit to see the difficulties that arise, usually in the evening ("after hours"), then relatives might at least feel that someone outside the situation knew what they are going through. (3) The present idea of waiting for the chief carer to express a desire to the doctor that the time may have come to send the relative into long-term care is mistaken, as some people will never be able to bring themselves to utter the words. (4) There should be a helpline available around the clock over Christmas holidays, instead of there being no support available at all for several days, at a time which is likely to be particularly difficult.

Question 2

ANSWER:

1. The administering of a "clot-busting" drug to the patient after an apparent stroke or TIA, as emergency care in the ambulance. It seemed that this then interrupted the pattern of strokes he suffered, and thus greatly prolonging his difficulties by protracting the illness (VAD) and his life. 2. I also know of a case where a team of paramedics in full gear rushed into a nursing home, surrounded a patient, set up a drip, administered oxygen, and prepared to zoom off in an ambulance with blue flashing lights to hospital - evidently an acute emergency case. The patient? A very sick old woman with end-stage dementia whose great misfortune was that she had not died before their arrival. Surely an obscene misapplication of medical skills in failing to let nature take its course and to put her through the indignity of any more medical procedures. What an absurd and tragic misuse of health resources! 3. Whether or not to administer antibiotics, a flu jab, etc. when in the Care Home and so to cure infections or prevent other

illnesses and thus make it harder to die. 4. The emphasis on care is on the dementia patient and seems not to regard the complex medical history of his carer or of others in the household. Many carers are themselves elderly and hardly fit for the task of coping with dementia in a close relative. 4. The exorbitant cost of care home fees. The prolongation of life at all costs can lead literally to the loss of a fortune in personal savings - something the patient would surely not have wanted. Moreover the money lost in this way could have benefited others who are not too ill to enjoy or profit from it, for example, as disability aids in the home, or eventually as care home fees for the surviving spouse, or as a charitable gift to benefit society.

Question 5

ANSWER:

Better understanding of the effects of drugs on the various dementia conditions. While recognising the need for urgent research, I regard research on animals as unnecessary, being inapplicable to the human brain and morally unjustifiable, especially given the diversity of other research methods such as computer modelling.

Question 6

ANSWER:

As soon as possible. There is an argument for scanning at a relatively early age, so that the state of the arteries can be seen and the likelihood of developing dementia assessed.

Question 7

ANSWER:

(1) There seems to be a widespread ignorance of dementia, society being divided into people who have experienced its effects and those who have not. (2) I have seen care assistants in a nursing home completely misreading the situation as they evidently understood nothing of the type of dementia or of the background situation of the patient. They treated my father as if he were simply an old man without illness, and even sought to blame his relatives for his distorted perspective. We were viewed with curiosity as though we were somehow responsible for him behaving in the way he did. One young person told me in tragic tones she thought it was terrible that "he did not even think he was coming to a nursing home; he thought it was your mother he was bringing". So much for the so-called person-centred approach referred to in this Consultation Paper, which seems to overemphasise the role and importance of the patient as if they are not ill, and at the expense of the interests and wellbeing of others around. And at another short-stay care home, my mother and I seemed to be blamed for 'letting him loose' on them without having fairly warned them what they were in for. Yet we could not have predicted all the difficult behaviour that happened. (3) Currently in society there seems to be

widespread misunderstanding and difficulty over the use of drugs such as sedatives or antipsychotics to control behaviour that is often otherwise impossible to deal with. In one nursing home, when in response to comments about my father's behaviour, I suggested the use of sedation, one nurse exclaimed in a horrified tone, "I don't think the doctor would want to do that!" In the second case, following a 15-hour tantrum of my father, the nurse and care home manager, utterly exhausted and at the end of his tether, said he did not want the doctor to think he "wanted to drug the patients up", and asked me to request sedation for my father from the GP. (4) A better understanding of dementia would surely be brought about if medical training required compulsory stays by doctors and nurses in residential homes or in families with a demented person. Nothing else can substitute for enforced observance and experience of the situation around the clock.

Question 9

ANSWER:

No, I think it should not. It is not fair to expect others to cope with the inevitable problems that result from patients with dementia wandering around, or misbehaving in waiting rooms, and so on. They should be cared for in an appropriate environment which, in my opinion, is a nursing home.

Question 10

ANSWER:

I find the idea of person-centred care to be of limited value, as the whole situation (i.e. of patient and other family members) needs to be taken into account. Please see my response to Q.7, para. (2), above.

Question 17

ANSWER:

People should be encouraged to make advance directives and these should be respected by law, but allowing flexible interpretation, so that appropriate choices can be made where something may reasonably be deemed "in their best interests", or in accordance with their character ("what they would have wanted") before they were ill. The organisation Dignity in Dying has produced one to help people take control over how they die, and supports voluntary euthanasia, a balanced consideration of which is surely key to a consultation on dementia.

Question 19

ANSWER:

Absolutely. For example, in order to prevent anxiety and difficult behaviour. Let common sense prevail in this and all other such matters.

Question 21

ANSWER:

Again, a matter of common sense. Restraint may be desirable and necessary for reasons of practicality.

Question 24

ANSWER:

Access to drugs, and to help and support, at all hours of the day and night. The state should help pay for the costs of nursing home fees and care.

Question 25

ANSWER:

By open discussion and flexibility of approach.

Question 27

ANSWER:

In many circumstances, for example, where the spouse has a serious medical condition or conditions, where the partnership is of a long duration, or the partner is emotionally or intellectually unable to cope with the demands of becoming a carer, is of a great age, of low educational level, has a cerebro-vascular condition, or may soon require nursing care themselves. The welfare of any offspring and pet animals in the family should also be considered.

Question 28

ANSWER:

Again, a matter of common sense.

Question 29

ANSWER:

It should be trying to prevent the onset of the disease, and to slow its progress where it has begun. Given the widespread increase of dementia, issues of general public health, such as water supply, should be considered. Funding to support research involving animals should be withheld.

Question 30

ANSWER:

I am not in principle opposed to involving people in certain types of research if they lack capacity to give consent, i.e. if it is too late to ask them, especially where they would have been likely to agree to it had they been asked before the

condition developed.