

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.

Professor Seth Love

QUESTIONS ANSWERED:

Q1

ANSWER:

The people who suffer most tend to be the immediate next-of-kin in their capacity as carers (usually the spouse or child). They spend years giving up most of their time, social lives, often sacrificing their jobs and potential income, looking after someone who is highly dependent on them for activities of daily living and no longer the person they remember. They need regular contact by and help from social services, and to know that the patient can regularly be admitted for high-quality respite care. They also need the patient to be maintained for as long as possible at a level at which he or she can still function reasonably independently for at least some of the time; even small therapeutic benefits (e.g. from cholinesterase inhibitors) can make a huge difference to the lives of the carers.

Q5

ANSWER:

Since the first elucidation of the genetic basis of some forms of familial dementia, we have made progress in understanding some aspects of the pathogenesis of Alzheimer's disease (AD). Advances have also been made in relation to familial Lewy body diseases, including dementia with Lewy bodies (DLB). The contribution of vascular disease to dementia is still poorly understood. Unfortunately, although we know much more than we did about how and why familial AD and DLB occur, in most cases the pathogenesis of sporadic AD and DLB remains completely obscure, and even in familial disease, the the scope for improving treatment is still severely constrained by the very limited understanding we have as to how and why these diseases actually cause dementia.

Q6

ANSWER:

With very few exceptions (e.g. hypothyroidism, hydrocephalus), the benefits of early diagnosis are unclear. At present we have no proven disease-modifying treatment. I think we should be open about our uncertainties and see no benefit in conveying the diagnosis before it is clinically certain. This may, of course, change if any of the drugs or immunotherapies currently being evaluated in experimental models and early clinical trials prove to be effective in modifying the course of disease.

Q11

ANSWER:

Most theories of the nature of human identity hold that the essence of identity is the states and processes of the mind and therefore the brain. These states and processes are, of course, profoundly altered in dementia, causing alteration and eventual loss of identity.

Q12

ANSWER:

It can be difficult to retain loving feelings for a patient with dementia and to continue to respect his or her previously expressed values and wishes, as that person's behaviour and personality progressively alter and he or she becomes more of a shell than the person that the family and friends once knew.

Q13

ANSWER:

In general I feel that the person's past wishes and values should carry a great deal of weight when decisions about them are made, particularly if clearly documented.

Q14

ANSWER:

The approach to strive for is one based on the consensual agreement of the patient and his or her closest next-of-kin (usually the carer), guided whenever possible by the wishes expressed by the patient prior to his reaching this stage.

Q15

ANSWER:

The considerations seem to me to be much the same as for other decisions concerning his or her care: as far as possible the decisions should be based on the wishes expressed by the patient prior whilst he or she was still competent but will need the involvement of the closest next-of-kin (usually the carer) in the decision-making process.

Q17

ANSWER:

My view is that these should carry strong weight in decision making, to the extent that they should be overridden only in unusual and unforeseen circumstances.

Q28

ANSWER:

In my rather narrow range of experience (i.e. speaking to patients and families who wish to make a brain donation for research), lack of information has rarely been a problem. The carer or carers have invariably been involved together with the patient in key discussions.

Q29**ANSWER:**

This is not a question to which there is a single simple answer. Research should be concerned with improving the accuracy of diagnosis in life, improving symptomatic treatment of the disease and working towards preventing, slowing, halting or even reversing the development of dementia. I am not persuaded that there is currently merit in trying to make a preclinical or very early diagnosis except in rare cases but this would, of course, change if we could modify the development of the disease. Most illnesses that cause dementia do so through a very complex range of deleterious processes that affect blood supply, neuronal communication, neuronal transport, removal of noxious agents from the brain, neuronal survival, etc, and we are still at a very early stage in trying to elucidate how and why these abnormalities occur, how they interrelate and how they might be prevented. There is an understandable desire to move very rapidly to trials of treatment but as far as dementia is concerned, the information on which these are based is currently very limited.