

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.

Susan Boex

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?

It is really a life changing diagnosis for the person and for the family. It must be very frightening for the person with dementia (my Father did not discuss it with my sister or myself. It is very difficult to have your roles reversed to have to look after someone who has always looked after you, we had all the problems mentioned above, behavioural problems, acting out of character, wandering off and always searching for something he could never find. It was especially hard for my Mother to gradually lose the person she loved when he no longer recognised her.

I think what is needed most is the help to be able to keep the person affected at home with their family for as long as possible.

Q2 What difference (if any) does a person's religion, culture or family background make?

I don't really think this makes too much difference. I know that some Asian and Indian families look after their elderly relatives better than we do, but I suspect that they may be more reluctant to admit that anyone has dementia.

I don't think in our case his family background would have made any difference to my Father. He came from a large but loving family.

Q3 When do you think a diagnosis of dementia should be made?

This is very difficult to answer. I personally think as soon as possible if there is a chance that drugs can be given to help. This relies on an early diagnosis. My husband was told wrongly that he might have the start of dementia, this was several years ago when he had an accident – it was found to be very high blood pressure that had caused it. It did make us get our affairs in order.

I do think some people would rather not know that they have it and would not have a blood test to find out.

Q4 Is the idea of person-centred care helpful? If so, in what way?

I don't think this really works because the person's life has changed. My father developed different ideas about people, sometimes saying things

completely out of character and sometimes even unpleasant and he also developed different tastes – although he always had a sense of humour and would often tell us corny jokes, sometimes he would chuckle to himself even when he did not know us.

Q5 Do you think that dementia can change people so much that they actually stop being ‘themselves’? -

Yes I do agree that this happens.

Q6 In your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?

I don't think people understand how much it affects your life – I didn't until it happened to us. I think we should try and change people's perceptions – by discussing it more in public – I do think this is changing but people do not know how to react to people with dementia and still think it will not happen to them

Q7 Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?

Yes – this is good in the early stages to live as normal a life as possible. We always took my Father out with us to have lunch in the pub and took him away on holidays until this proved to be too difficult.

He did not like the day centre we tried to take him to later on but he was always a private person and did not mix very well in any case.

Q8 What duties do you think the government owes towards people with dementia and their families, and why?

I don't know if I agree with the phrase “the government owes” I think it should have a duty of care and it needs to understand how much this disease affects peoples lives. We were really lucky to be able to send my Father into respite care at a local purpose-built unit for a week every month for a short time until this facility was closed down. After this my Mother had a heart attack and my Father had to go into full-time care – she had to pay for his care. All he had was the medium rate allowance this after working hard all his life, he was unable to enjoy any retirement and had saved towards this all his life and was penalised by the government for this.

The government should give the full care allowance at least not based on nursing care. My Father could not do a thing for himself if someone had not fed him he would have died. Yet we still could not get the full allowance. My Mother spent a large part of their savings on his care,

selling their bungalow for a flat. Once he was in the care home that was that – my Mother had no support – not even a visit from Social Services.

Q9 How do you think a person's *past* wishes and feelings should be balanced with their *current* wishes and feelings, if these seem quite different? Is the past or the present more important?

I think the patient's earlier wishes should be taken into account when they were able to express their true feelings. Later on it can only be the family or carer's wishes for that person.

Q10 What do you think family or friends should do if they are worried about the decisions a person with dementia is making?

Again this is very difficult in the early stages, my Father started drawing money out of the building society and hiding in the house. We did try to explain to the building society and then someone always tried to go with him. I think we were lucky again in having family to call on – it must be very difficult if that person was living on their own. There must be some intervention by family if people are making decisions out of character that are harmful to them.

Q11 Should people be encouraged to write advance directives? How should they be used?

I think it is difficult with patients who develop dementia to keep to an advance directive – they may say they do not want to go into a nursing home but it may be impossible to keep to their wishes in their "best interests".

Q12 What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

You would hope that the Doctor would be the best person to decide on questions such as whether to give drugs to calm a person down. The welfare attorney if it is a close relative is sometimes too involved or distressed to see the clearer picture. This is just from one personal experience of a patient's wife refusing to allow drugs to be given when it was obvious this needed to be done. I think the welfare attorney's views should be taken into account though as hopefully some compromise or agreement can be reached without distressing anyone.

Q13 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

I think there should be a gauge in telling lies, we told my father “white lies” to help him feel less distressed. I think the care of the patient must always be paramount

Q14 Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?

This is very difficult – it may be ok at first not to be too worried, my father used to try and make the tea for my Mother as he always did, then he started making it with cold water, then once he put the plastic watering can, used for watering the house plants, on the electric cooker and turned it on and as they lived in a flat at the time this was very dangerous. I think you really have to be sensible about things at this later stage.

Q15 Should any forms of restraint be allowed? If so, when?

Yes, I think some form of restraint is sometimes necessary. Some people do have personality changes and this can become dangerous for people looking after them. We were lucky in that my father became very stubborn and occasionally lashed out and refused to do anything, but he was never violent. Of course it is always better to try and defuse the situation or avoid the “triggers” but this is not always possible.

Q16 Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?

It is easy to say that such things as tagging affects people’s privacy, but if you have ever been through an experience of losing someone who has wandered out of the house and on to a main road – and you can’t find them even if it is only for a short time – it does make you frantic until you know that they are safe so I would agree with limited use.

Q17 How can professionals (such as doctors and social workers) help if a carer’s own needs are very different from the needs of the person for whom they care?

My Mother carried on looking after my Father until she had a heart attack herself. She would have benefited from help a lot earlier but would not ask for it!!

Q18 Is it too difficult for family carers to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?

I think it is much more difficult nowadays to share information about patients. Fortunately in our own case, my parent’s GP was exceptionally understanding and involved all the family as far as possible. When my

Father went into a care home this was much less possible and we were not kept informed all the time.

Q19 What should research into dementia be trying to achieve? On what basis should funding be allocated?

For me the most important thing is to try to find a cure for this cruel disease so this would be my personal priority. This takes a long time so I think it is equally important to try and find treatments that can slow down the damage and to find better ways to support and care for patients. I agree with the Alzheimer's Society policy of cause, care and cure. But more money is needed for research!!

Q20 What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?

We were not offered any treatment for my Father. If we had have been offered the opportunity of giving him a drug that would have potentially helped as a trial we would have done so. It was a living death for him, he did not remember us or recognise us, could do nothing for himself and we were helpless – people must be given the opportunity to try and reverse this condition provided of course that they are not upset or suffer ill effects from treatment.