

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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QUESTIONS ANSWERED:

Q1

ANSWER:

Social isolation is one of the aspects of dementia which has a colossal impact on those who have dementia and their carers. There is a pressure to seem 'normal' and when the person with dementia can no longer manage to seem normal, friends fall away and there is reluctance to go into social situations for fear of inappropriate behaviour. This means that more and more people are being hidden away at home and in care settings. If we are not careful we will reproduce the way we managed people with mental health problems until relatively recently. We need social settings where people with dementia and their carers can be part of what is happening. Alzheimer's Society work with this idea and we need to make sure this attitude prevails elsewhere.

Q2

ANSWER:

Where there is a dissonance between the needs of the person with dementia and the needs of the carer. For example the person wishes to remain at home and the carer wishes them to go into care. Deciding when stop trying to 'correct' the person in order to bring their perception of reality into line with others.

Q5

ANSWER:

I feel that it is vital to focus not only on 'miracle cures' but also on the quality of care for people with dementia. Early and more definite diagnosis could lead to crisper overall care.

Q6

ANSWER:

I think a diagnosis should be made and communicated to the individual as soon as possible but not BEFORE dementia symptoms become evident. The stigma itself must be worked on rather than reluctance to diagnose just in case diagnosis may be incorrect.

Q7

ANSWER:

Society is afraid of dementia as it is another form of difference and society does not deal with difference. We definitely need to promote a better understanding of dementia. This could happen through programmes in community centres focusing on dementia, television campaigns, education in churches and other community groups.

Q9

ANSWER:

More should be done to include people with dementia in everyday life. This could be part of inclusivity programmes which all sorts of organisations could be invited to join. It might then be possible to plan outings, for example to eat out without fearing strange looks if someone is playing with food in an unusual way.

Q10

ANSWER:

The idea of person centred care is helpful because it puts the person first rather than the dementia. Each person has an amazing history and is the product of their place and time. To see that person as an example of a syndrome would be most unhelpful. The way we view the person affects the way we treat them and it is much more difficult to treat someone carelessly if we are remembering their humanity all the time.

Q11

ANSWER:

I feel that dementia changes a person's behaviour and not their identity. Some aspects of character might become more pronounced and people might revert to ways of being which they adapted in adult life but the person is not lost. Memory is lost but memory is not the whole story.

Q17

ANSWER:

Advance directives seem very helpful and if made should be taken into account when making decisions about the person with dementia and their care. It seems a good idea to encourage people to complete them. I would certainly like to be able to complete such directives after a diagnosis of dementia.

Q20

ANSWER:

In my experience people caring for those with dementia err too much on the side of caution. Clearly much care and caution is needed but it is crucial to weigh the risks and remember that the person should be as free as possible. How many times does a person with dementia get told to sit down. Why? Often there is not

reason except the convenience of the carer.

Q21

ANSWER:

Restraint need to be available as a last resort when a person with dementia is endangering another person physically or emotionally.

Q22

ANSWER:

Education in ethics of decision making needs to be considered as part of the training for those working with people with dementia. This would necessitate an investment in the quality of dementia care. For individual carers it can be part of the support system provided by Alzheimer's Society and others.

Q24

ANSWER:

We owe a duty of care to those with dementia as they have made a huge contribution to our society in the past. We cannot write them off now that they have become vulnerable. Any state can be judged by the way it cares for its vulnerable members.

Q25

ANSWER:

These issues can be resolved by counselling the families. All agencies should be involved. Clearly this would mean a commitment in terms of money but a way forward could be worked out carefully and thoughtfully between all concerned.

Q27

ANSWER:

In cases of abuse or dangerous neglect it might be necessary for health or social care professionals to make decisions.

Q29

ANSWER:

My feeling is that research should prioritise improving the quality of care for people with dementia and improving our understanding of the processes which lead to dementia. Clearly there also needs to be research into drugs which might help in the future but that seems slightly less important though it may seem more sexy and dramatic.

Q32

ANSWER:

We need to concentrate on bringing dementia into the public arena as much as possible so that people are encouraged to weigh up the issues involved before they or their loved ones receive a diagnosis. This seems to me to be an ethical issue.