

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:

For the person with dementia: inability to continue with their lives independently; frustration with their condition; shock at the initial diagnosis. For their family: coping with behavioural changes; 'losing' their family member as they knew them; For carers (family members): coping with 24/7 caring For society: dealing with the number of people with dementia requiring care. There are not enough staff/facilities to cope with present numbers, let alone future ones. Support required: practical help as currently provided by social services, but also psychological help to deal with possible side effects, such as depression.

Question 2

ANSWER:

Whether to tell them the truth in certain situations. Either with the initial diagnosis, or in daily life eg if they ask 'are the children fed' or 'where is my mother', where the children are grown up and the mother long dead. Also dealing with medication - whether or not to hide it in food when they are unwilling to take it, but it would benefit them to do so eg calcium tablet.

Question 3

ANSWER:

I don't have any personal experience, but I do feel that different cultures should be taken into consideration, eg if a person with dementia is of Jewish or Islamic faith, and they followed their faith, they should not be fed pork.

Question 4

ANSWER:

I have no personal experience of this, but ethical questions would probably include how to justify treating people in different ways, eg not allowing certain religious people to eat prohibited foods, whilst everyone else around the table can eat what they like.

Question 5

ANSWER:

I am aware of relatively new medications which can treat dementia in the early stages, and also of experiments being undertaken with animal models at Southampton University. Anything which will detect, prevent or cure dementia is vital. Also, recognition that infections, hospitalisation can worsen dementia,

so care should be taken to avoid such situations.

Question 6

ANSWER:

As early as possible, as I believe the advantages of obtaining early medication outweighs the disadvantages of mis-diagnosis. Knowing what lies ahead, the person concerned and their family will also be able to plan for the future.

Question 7

ANSWER:

It is generally perceived as a symptom of old age, and relatively little is known about it. Personally, until my family member developed dementia, I had no idea of what suffering it involved, or how it would progress. I was given no info from social services on what to expect, but did my own research through books, the Alzheimer's society, Alzheimer's cafe meetings. We do need to promote better understanding - through public education via TV, radio, press, internet. Also through public figures, such as Terry Pratchett, who are not embarrassed to reveal the fact that they have this disease, but try to make more people aware of its existence.

Question 8

ANSWER:

Amongst some families, yes, there is stigma attached. Some family members no longer want to be associated with the person with dementia, and only want to remember them as they 'were'. I have not noticed any stigma in care homes.

Question 9

ANSWER:

Yes, make them feel a valued member of society, by joining in family activities, encouraging them to join/continue with social clubs. Encourage them to continue with their normal life for as long as possible. Offering support such as transport to various activities if necessary.

Question 10

ANSWER:

Yes - all aspects of care need to be taken into account, not just physical. The person still has an inner life and we owe it to them to respect it eg take them to church if they were always church goers, even if they are disruptive. We need to identify why they behave in certain ways; identify what triggers certain behaviours/emotions; what scares them; what makes them laugh.

Question 11

ANSWER:

Superficially, yes, they can seem totally different to the person they once were. But within they still have the same identity and that should be respected. They definitely still have momentary insights into their condition and can understand what is happening to them.

Question 12**ANSWER:**

Radical changes can put a great strain on relationships. It can be extremely stressful to deal with a person's anger when they were once a very quiet, loving, caring person. It can be difficult to respect their previous values and wishes if they no longer seem to hold them eg if they always enjoyed walking outside, but are now abusive to people they meet.

Question 13**ANSWER:**

The person's past wishes should override current wishes, especially if current wishes are not in their best interest eg if a person always took good care of their cleanliness and appearance but now does not want a bath because they do not like being hoisted, then they should still be given a bath.

Question 13**ANSWER:**

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Question 14**ANSWER:**

Respect their current wishes unless they are harmful to themselves or to others eg if continuing to live on their own would expose them to too many dangers then a rest home may be the best option.

Question 15**ANSWER:**

Past wishes should be paramount - if they are known. If the person did not want to live with dementia, they should not be forced to. They may seem happy, but we have no idea how tormented their minds really are. If past wishes are not known, this should be a joint decision between family members and health

professionals.

Question 16

ANSWER:

Welfare attorneys who know the person well and have their best interests at heart should make the decisions. All disagreements should be resolved by discussion and not resort to court rulings.

Question 17

ANSWER:

Advance directives should outweigh any other decision making process, as these would have been made when the person was still in full control of their faculties and could fully express how they wished their life to end. Everyone should be encouraged to complete these - in the same way as making a will.

Question 18

ANSWER:

No personal experience of these Acts, but both seem very confusing and conflicting if both past and present wishes need to be taken into account.

Question 19

ANSWER:

Definitely - they are generally looking for reassurance, comfort and support. It would not be in their best interests to say that their husband was dead, if they asked when he was coming home for tea. This would only distress them and possibly re-live past traumas.

Question 20

ANSWER:

In my experience they get it about right. If bed rails prevent a person from falling out of bed and breaking their hip, this is obviously in their best interests. I don't believe freedom of action should override sensible decision making regarding safety. Freedom of action is generally overemphasised in society as a whole.

Question 21

ANSWER:

Yes, if they are likely to harm themselves or others, eg by being aggressive. I agree all actions must of the least restrictive type, but this must be balanced with the welfare of others and resources available. Decisions should be made by the carer dealing with the situation at the time. I think the law probably hinders carers as they are too concerned with making the wrong decision and being

reprimanded or even sued.

Question 22

ANSWER:

In care homes you would assume carers already have this training, but for family members who are carers, yes, I feel this is essential. Through specific classes, videos/DVD's, various websites, Alzheimer's Cafe's.

Question 23

ANSWER:

They may be seen to compromise individual freedoms and be an invasion of privacy. But these issues should not override the question of personal safety of the person concerned. Some of the new technologies are probably not more widely used because they are not known about, or because carers are concerned of compromising individual freedoms.

Question 24

ANSWER:

Treat their illness in the same way as any other disease, such as cancer, heart disease. Care should be free - if people wish to take out policies to provide for better care, they should be encouraged to do so (though private homes are not necessarily better than state homes). The same standard of care should be available to all - a basic tenet of the NHS. The state should most definitely NOT be allowed to force people to sell their homes to pay for care. They may have scrimped and saved all their lives to buy a house, only to have it taken away from them, whilst others have paid no regard to saving for their old age.

Question 25

ANSWER:

A sense of balance needs to be achieved. Ultimately, the carer's well being should be taken into account if they are stressed/depressed/worn out with providing constant care. It will not benefit either party if the carer is too tired to carry out essential duties.

Question 26

ANSWER:

Professionals should step in if they notice conflicts of interest, and assist in sensible decision making. They will be forced to decide which person's well-being should come first.

Question 27

ANSWER:

If the couple's interests are best served as being treated as a couple - it would surely be more humane to house a couple together than in separate homes if they have been together for many years.

Question 28**ANSWER:**

Too little - family carers need to know their history to make correct decisions. If there is confidential information unrelated to their condition, this need not necessarily be disclosed, but anything relevant should be made available. Information should always be disclosed in private.

Question 29**ANSWER:**

Find an early diagnosis, a way to inhibit the disease, and ultimately a cure. Funding should be based on the percentage of people expected to suffer from dementia.

Question 30**ANSWER:**

If possible, this should be included in their proxy consent. If not, then this should be based on their perceived attitude to research. Some would not mind taking part in any type of research if it would benefit others; others may draw the line at medication and not want their brain cut open to view the extent of tangles. If views are totally unknown, they should not be made to partake in any research.

Question 31**ANSWER:**

No - research is important, but should only be carried out with consent, whether actual or perceived.

Question 32**ANSWER:**

Not sure if this is an ethical question, but the question of language does pose some challenges to carers. Many people with dementia may be from different nationalities and will invariably regress to their first language. If there are no carers around who can understand them, this can pose issues on how to treat them. eg if the person in question is complaining that they are thirsty, but no-one can understand, they may become dehydrated.

