

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.

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?

For family and loved ones, I think the changes in the persons character and any cognitive difficulties have an enormous impact as they often deal with physical problems more practically and therefore they have less emotional impact.

Support needs to be proportionate and as non judgemental as possible... the person with dementia is not being "naughty".

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

These factors have to impact on both the person with dementia but perhaps more obviously with how the family cope with the progress of the illness and the challenges it presents.

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

I think it is a term that is banded about very readily by professionals and my experience is that family can often feel it is political correctness gone mad and an excuse for their needs and wishes to be overlooked giving preference to the person with dementia when they can clearly see that person can sadly no longer make the decision. For instance in daycare a frequent complaint from family is that their loved one returns at the end of the day having been incontinent of urine and are told by staff that "he didn't want to go to the toilet when they asked and they couldn't force him". The end result is that the wife has to struggle to change him alone and feels that respite that was supposed to help her has not met those requirements.

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

No, I feel that they become a different version of themselves. I have often noticed that personality traits that existed before but maybe were moderated (either consciously or not) become more evident and although sometimes distressing this is still a snippet for the loved ones of the person they used to know.

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

I think society has a lot of empathy/ sympathy for both those with and caring for someone with dementia.

What they know about the condition usually comes from the media and news worthy stories and tends to dwell on the tragic and end of life issues. As is usually the case the mediocre (day to day struggles) does not provide enough sensationalism for tv/ newspapers and maybe making this more common place on tv in sitcoms etc would help the perception of people towards those with dementia.

I am not sure how much people understand the plight of those with early onset dementia as it is more unusual and one is less likely to have experienced in ones own life or family.

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

This could only promote more understanding and make it less frightening for all members of society, as ignorance is largely what promotes prejudice. It might also have the knock on effect of making it more appealing for young people to take up employment in the caring professions especially nursing homes etc where they could play a huge role in care of this and other groups of elderly people.

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

I feel they need and should expect simply the same level of care and support as anyone else with a disability.

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?

Their past feelings and opinions will often somehow be reflected in their present ones ... often to do with family / societal values they were very committed to... however their present wishes can often be conflicting with these and if followed lead to poor care and the detrimental effects of this.

Surely this is why they are often considered to be Vulnerable adults who need support outside of their immediate family to ensure reasonable and sensible interpretation of their expressed wishes. This needs to be made more public and accepted more as support rather than interference often in situations when a persons human rights are being abused by family. Families donot always behave in a loving manner!!

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

They should ask to speak to a professional who could assist with the situation and offer advise on how to proceed. If Social Services intervention was portrayed in the media in a more favourable light maybe it would not be automatically seen by family as an admission of failure to contact them for assistance.

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

I think an expression of your wishes when you are still able to do so can only be seen as a positive addition to determine the direction of your own care when you are no longer able to decide clearly.

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

Truth is not always cut and dried.. ie, omitting to tell someone something that could distress them could constitute an untruth but most of us could easily see situations when we might do this. I feel that as the person with dementia becomes more estranged from the real world it can sometimes be kinder to omit the truth and especially when they are, for instance more likely to refuse medication etc if they are made too aware of the facts.

The world that a person with dementia inhabits is not always the one their loved ones and carers are still living in ..with its time and resource constraints, as well as those society places on us to conform and I think a sensible balance of truth and "white lies" should be allowed.

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?

As the person with dementia does not have a realistic concept of risk they cannot clearly be left to follow their own decisions on all occasions. A balance of risks is needed to allow them some freedom of action whilst not putting them at unnecessarily high level of risk. There are usually ways to limit risks and I think in general carers and loved ones become very adept at balancing these two elements.

Unfortunately, professionals who do not know the client well may be the ones to introduce too constraining a management style in their efforts to protect a client but in working closely with carers this can often be made more acceptable. Finding a balance and accepting risk is an important element of a therapist's training... accepting we cannot eradicate all risk and shouldn't be trying to do so is a difficult but essential fact to accept.

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

I would hope that a trigger would be looked for and often try to explain to carers that there is no point in trying to restrain a client but to accept the behaviour and work with it... ie, people with dementia often seem to "grab" at doors, slings etc and I usually try to substitute what they have grabbed unusefully with something they can safely hold rather than trying to stop them grabbing per se.

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

Surely if they allow the person to live more independently and safely they are a bonus and should be further developed and the fact that they include outside observation should be monitored but not blown up out of all proportion. The alternative living dependent on others I would argue is more of a liberty on their rights. Perhaps these sort of eventualities and dilemmas and the possible acceptable solutions should be included in the Future directives drawn up by people diagnosed with dementia as well as care and end of life issues .