

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:

Q1. Difficulty with, or loss of communication is definitely one of the most distressing and frustrating aspects of dementia for the individuals with the condition, their family and society as a whole. Identifying alternative or augmentative communication methods would alleviate some of the distress which loss of communication can cause, and ultimately improve quality of life both for individuals with dementia and those who care for them. One such method is Talking Mats, a low-technology communication framework developed at the University of Stirling to help people with communication difficulties to express their views. It uses a simple system of picture symbols and a textured mat that allow people to indicate their feelings about various options within a topic by placing the relevant image below a visual scale. A recent study has shown that the Talking Mats framework could be used by many people at all stages of dementia and that it improved their ability to communicate compared with usual conversation (see www.jrf.org.uk).

Q2

ANSWER:

Q2. Situations where decisions are made for the person with dementia without their input or in consultation with them raise ethical concerns. For example, decisions are often made about future care without actually asking the individual their preference or opinion. Although difficulty with communication can make discussions around this issue difficult, the person with dementia has a right to express their view and time should be taken to assist them work through the thought processes involved in decision-making, and use suitable methods to allow their view to be heard.

Q6

ANSWER:

Q6. The timing of diagnosis should be on a case-by case basis. Individual personalities and temperaments will determine how each individual will cope and react to a diagnosis of dementia. For some individuals, an early diagnosis may cause distress and lead to feelings of despondency and hopelessness. For others, early diagnosis may offer some relief and allow them to better understand their changes in behaviour and empower them to seek strategies to cope. Family members and professionals should consult closely to ensure the

best decision is made for each individual involved.

Q7

ANSWER:

Q7. Although society's understanding of dementia has increased there are still large pockets of fear and ignorance. To many, dementia is still seen as an 'old person's affliction', even though more younger people are now diagnosed. Many are still fearful of a diagnosis of dementia, thus increased education is necessary. One way to tackle this is to educate our children in schools about the condition, and provide facts to combat the fallacies. As our population are living to an older age and more people are diagnosed with dementia, there is an increased chance of a child having personal experience of dementia through grandparents or other relatives. If we can teach children the facts about dementia and help them to understand changes in behaviour, perhaps this will alleviate some of the fear and help to combat the ignorance in future generations.

Q9

ANSWER:

Q9. Yes - but only if the person with dementia wants to - often people's interest and motivation change as dementia progresses.. We have found that the Talking Mats framework is one way to allow the person with dementia to express their views about their interests and what they wish to be involved in.

Q12

ANSWER:

Q12. The onset of dementia places extreme strain on relationships and family ties. The child of a person diagnosed with dementia often does not recognise their parent as their parent. Roles are reversed, as they now have to look after their parent, as opposed to their parent looking after them. Often the children of individuals with dementia are torn; they were raised with, and remember their parent's values and beliefs prior to the onset of dementia, but can find it difficult to encompass these values and beliefs when trying to make the right decision about their parent's care.

Q13

ANSWER:

Q13. As far as possible both past and present wishes should be encompassed into any decisions made. Such examples could include: if the person with dementia expressed a wish to remain in their home town prior to the onset of dementia, then care options in that area should be explored. Similarly, if the individual had a strong faith and regularly attended church then care options which could accommodate this need should be sought. In short, their beliefs and

values both prior to and after diagnosis should be considered. Although a person who lacks capacity may not be able to make crucial decisions solely, methods should be employed to involve them as much as possible in the decision-making process.

Q14

ANSWER:

Q14. A common sense approach should be employed. As discussed previously , as far as possible the views of the person should be considered regardless of capacity.

Q17

ANSWER:

Q17. In our view advance directives for all individuals should be encouraged. Having a record of an individual's wishes would help to ease the guilt, confusion and hurt that often ensues when forced to make decisions for our loved one's care, most especially when distress and/or pain are evident.

Q18

ANSWER:

Q18. Both! Harder that we are now forced to ascertain the person's capacity to understand and make decisions but easier in that relationships with person with dementia are ultimately better when their views are considered.

Q19

ANSWER:

Q19. Not telling the whole truth to any individual - not just a person with dementia - is acceptable if the truth will cause them unnecessary anguish or pain. As previously mentioned, some individuals may react negatively to adverse news, which may hinder their prognosis and/or quality of life. The judgement on the level of truth to be told should be based on each individual and their anticipated response.

Q24

ANSWER:

Q24. The state must ensure that the individual with dementia retains their rights and dignity just like any other individual, regardless of their diagnosis. They are still important members of our society and have contributed to the state throughout their lifetime prior to their diagnosis. Thus, the state has a duty to make every individual's life during times of illness as comfortable as possible. Adequate financial and emotional support for carers should be offered to ease the stress and financial hardship incurred when looking after a person who is

chronically ill. Improved care options such as specially trained staff and care facilities whether residential or day care services should be available across the country. Palliative care for individuals with dementia also needs to be addressed.

Q25

ANSWER:

Q25. Facilitating communication between the person with dementia and their carers is crucial to avoid conflict. Both parties must be allowed to express their view and try to work together to make a decision. A record of what was discussed and decisions made should be kept for referral and should be reviewed on a regular basis to check if views or circumstances have changed. As mentioned previously, the Talking Mats framework could offer a way to maintain communication and provides a visual record of a discussion, lessening the cognitive load and aiding the difficulties with communication so often evident in dementia. (www.talkingmats.com)

Q

27

ANSWER:

Q27. When the health (either physical or mental) of the members of the household is compromised, and the support system of the person with dementia is in danger of collapse.

Q29

ANSWER:

Q29. · Elucidating the possible causes of dementia: Genetics? Environmental? · Epidemiology: longitudinal studies, multi-centre, worldwide · Bio-markers – aid early diagnosis and commencement of treatment · Slowing down the deterioration of cognitive function · Stem cell therapy? · Quality of life: allowing the person with dementia to be heard – communication aids, decision making tools

Q30

ANSWER:

Q30. This type of research is imperative as although progress has been made in animal models of medical conditions, how can we be sure that they wholly translate to human models. For this reason, involving vulnerable individuals in research is acceptable as long as strict consent procedures are clearly mapped. Ongoing consent and family consent should always be sought. The research itself should also be relevant to the individuals involved and not just research for research sake or purely theoretically driven. We firmly believe it is important that we – as scientists – embark on empirical research that is not only of interest to the scientific community, but more importantly is also meaningful and of

practical importance to the participants who so willingly take part.