

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.

Elizabeth McIntyre

Q1. The loss of social interaction as other people find it difficult to visit when a friend has dementia

Q2. Being on the waiting list for surgery by the time the patient came to top of list he was unable to consent fortunately the Dr involved was very patient and after a long time talking with him felt able to carry out the surgery this made his last Christmas so much brighter and for the next few months he was able to enjoy his surroundings so much more than the 2 years prior to surgery

Q3. would think this would have some differences

Q4. am unable to talk on it no experience.

Q5. The idea of smart houses sound a fairly good idea I would struggle with tagging a patient.

All patients should get the opportunity to try any new medication it may not be for all but we have to give them the chance.

Q6 There are good reasons for early diagnosis i.e. the person will know what is wrong disadvantage :other people talk down to them and they still have most of their understanding

Q7 I found people talk to them as if they are deaf or don't understand anything talk to them as if they were toddlers. Yes we have to promote a better understanding so they are treated like adults but with time and patience.

Q8. I think a great deal of how they think they will be treated causes the patient to delay help.

Q9. Yes I think we should have patients with Dementia included in everyday communities as this gives them a chance to say what they feel will be of help to them.

Q10. Yes a lot of patients are still able to say what they need or want.

Q11. it appears to change them in some cases a lot. My husband was a very good natured very chatty person liked to be at the centre of a group by the last 2 years of his life he remained very good natured but he did not talk at all and when a very vocal person stops talking or trying to communicate then it feels like a different person .

Q12. In some cases the patient becomes violent this might be because of the frustration of not being able to carry on as before when this happens it must be very difficult for relationships to carry on as before.

Q13. If things have not been talked through before getting to this stage those who care for and who know the person have to make the difficult decisions

Q14. The patient should be in on the talking time and it should all be done with people who know the person as well as possible.

Q15 I do not think it should change things my husband and I had talked about life sustaining treatments long before he had dementia at the same time as we talked about wills and what we both wanted at our end of life.

Q16. These problems can occur in any patient at end of life time even when the patient is able to make decisions in some cases we have health care professionals who think they know what is best regardless of what the patient wants I think it is important for those who have been picked by the patient as welfare attorney have to be taken as if speaking to the patient.

Q17. I think they should be used as the patient has done this in the expectation that his /her wishes are going to be put in to practice.

Q19. I was fortunate in never having to lie I don't like the idea of lying to any patient [ I was a nurse for 40 years] but I have not walked in the shoes of the person who feels they have to do it so I could not judge anyone on this.

Q20. Yes I think everyone is inclined to behave in a defensive manner and yes some freedom has to be allowed even at some possible risk.

Q21. This is a very personnel view but I could never agree to restraints for any reason.

Q22. When the person is in care then the staff should be able to be trained with ethical issues.

Q23. Smart homes I think are good but tagging to me is like restraints I could not get involved with them.

Q24. Different people need different help so it should be flexible to requirements

Q25. With great difficulty and lots and lots of PATIENCE

Q26. Just talking through problems with an outsider can often show a new light on things.

Q27.when the carer is under so much stress that both carer and patient are at risk.

Q28.When I was my husbands carer I was the one who had all the information and it was me who told any help I had what I felt they needed to know.

Q29.Cure and cause, funding needs to be increased as the the numbers of people with dementia are increasing for several reasons the main and obvious one is we are living longer

Q30.I feel a little uneasy about using people who are unable to consent unless they have discussed it with someone before becoming unable to consent.

Q31.NO.