

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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Q1: Loss of memory, inability to communicate as well, behavioural difficulties, and support should include a patient non-patronising carer (full Time)

Q2: Religion and culture should always be considered, especially when it comes to treatment. The patient may not be able to express these wishes so good communication with family will help.

Q3: Diagnosis should be made ASAP so patient and family can prepare themselves.

Q5: Yes, although it is very important to remember that the person hasn't chosen to be that way. It is the result of the disease whether directly or indirectly.

Q6: I think it is more a case that society doesn't know enough about dementia and doesn't understand it, leading to 'fear of the unknown'. Dementia needs to be promoted as a clinical disease and that behavioural changes are due to chemical changes in the brain.

Q8: Good support service – advice on care and benefits as patient likely to be unable to work.

Q9: Their mental status needs to be considered. It may be that they are confused and don't really understand what is happening. I think previous wishes should be given high priority where the patient is in a later stage of disease.

Q10: Speak to medical professions about assessing whether they are in a position to understand what is happening.

Q11: Advance directives are a good idea but people change their minds and may not realise how later stages of the disease will affect them. I think it should be up to the patient and should be respected throughout life.

Q12: If the person with dementia is likely to say no if they were able, the welfare attorney should too and the doctor should explain why he thinks differently but should respect the patient's wishes.

Q13: If the lie is only a slight lie or just the truth made a bit simpler then the patient may understand better and therefore be less aggravated.

Q14: As long as supervision can be provided there is no reason why someone should be denied freedom action.

Q15: Only if the patient is physically harming either himself or someone else (carer, medical professional etc). Not at other times.

Q16: I think there will be low compliance for electronic tagging even though it may be useful for many dementia patients. Any monitoring should be minimal and should not affect the day to day life of the patient. Safety installations should not raise ethical issues as health and safety should come first with the patient.

Q17: It may be a case that the patient just wants someone familiar close all the time, in which case other family members or friends may be able to accompany the patient for a while. A stressed or tired carer would not be helpful to the patient and could aggravate emotional stress further.

Q18: Immediate family should be told the facts if the patient is incapable of doing so in order to provide the right care, but only relevant information.

Q19: Research is needed in all of these areas, but finding a way to stop or reverse the damage is as important as prevention as currently diagnosis comes late on in disease.

Q20: Advance directories should be considered, but it is advisable to discuss this with the patient prior to advance disease. Consent be immediate relatives should be allowed.