

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 2

ANSWER:

At what point do you/should you intervene in a persons life and activities in order to prevent them from potential harm (e.g. driving or going out on their own)

Question 1

ANSWER:

Potential risk to self if not supported. Frustration of the individual who realises they have symptoms. More information needed for carers on how to manage symptoms in a positive way.

Question 4

ANSWER:

The beliefs and backgrounds (religious and cultural) should be considered but never assumed.

Question 5

ANSWER:

More work is needed regarding the general health of patients with dementia and also on earlier/more accurate diagnosis.

Question 6

ANSWER:

Yes

Question 7

ANSWER:

An inevitable result of ageing. Some people perceive as an entirely negative disease others see some aspects of dementia as beneficial (mental decline results in lack of worrying about oneself and sometimes more humourous approach to life).

Question 8

ANSWER:

Assumptions are made that those with dementia have less understanding and awareness than they actually do and decisions are made for patients based on

assumed lack of capacity.

Question 9

ANSWER:

This depends on the individuals involved.

Question 10

ANSWER:

Very much so. Need to treat the whole person not just one set of symptoms.

Question 11

ANSWER:

Outwardly those with dementia often appear to have changed a lot but often if we make enough effort we can see that inside the person is still the same. People with dementia don't suddenly change.

Question 13

ANSWER:

Assessment of best interests must be based on what we (whoever that is) believe the individual does/did/would have wanted for themselves not what others or ourselves would or should want if it was them in the situation. This is hard to distinguish and often family members and medical staff act in the perceived best interests of a patient based on their own values not the patients.

Question 16

ANSWER:

If a welfare attorney is a relative (most likely) again there may be conflict between the individuals actual views (if they had capacity) and the perceived views. Carers and family members are often biased albeit accidentally and may not be best placed to represent the individual. If someone gave power of attorney 20 years prior to losing capacity a lot may have changed in terms of family dynamics/relationships. Access to independent welfare attorneys may be a better view as they are not emotionally involved. Health professionals should advise the relevant person who has capacity to decide but should not enforce their own views.

Question 17

ANSWER:

Option 3 - people change their views and values over time so an advance directive should not be the only deciding information.

Question 19

ANSWER:

No Better option is to distract the person and/or change the subject if it is distressing to the person.

Question 20

ANSWER:

Too much

Question 21

ANSWER:

Only to prevent harm and not to make the caring situation easier or because of a perception that we know best.

Question 22

ANSWER:

Yes - would need to be a range of methods, advice from GPs or practice nurses who are caring for the patient. Advice on site at hospitals.

Question 23

ANSWER:

Consent and liberty/human rights versus harm reduction Resources needed to make any technology effective - if someone is tagged who is watching and tracking.

Question 27

ANSWER:

In the instances of a husband and wife or partners who have different needs (e.g. one with dementia one without) it is absolutely disgraceful that the cost of care is used to decide that they cannot be placed in a care home together (providing appropriate care for both is available). This should be an over-riding factor when deciding on appropriate care needs unless the couple request otherwise.

Question 28

ANSWER:

Past history and views of patient need to be taken into account. Provision of all information can result in inappropriate disclosure of medical history (e.g. a mother who had a child prior to marriage). This needs to be balanced against supporting and enabling the carer to care for the patient - i.e. being able to book

appointments or receive test results on behalf of patients (currently this is an issue with the wondrous Choose and Book system).

Question 32

ANSWER:

Often carers do not want to access support even when it is available (for reasons of pride or 'talking' not being the way they deal with things). More practical help should be offered and as a byproduct contact with professionals (e.g. talking to the benefits officers) will provide support. More attention needs to be paid to the consistency of care and attitudes of all health professionals across the sectors. The remit of home care needs clarifying. It should be made absolutely clear if and when a health professional does and is able to act against the wishes of either the individual and/or family and documented in the patient's notes. Impartial support (e.g. PALS/Chaplaincy etc) should be involved to allow carers and family to sound off and/or complain if they feel their views (and the patients) have not been taken into account even if they understand deep down the reasons why.