

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:

NOK and dr-patient confidentiality. The family were aware of these difficulties and were not requesting information, they wanted to give the dr some information which could be useful for the dr to provide the best care for their relative. The GP refused to listen to any information or concerns and 'hid behind patient confidentiality'.

Question 1

ANSWER:

Frustration both for the patient and the family e.g having to repeatedly answer the same questions again and again. That the patient cannot be left alone, especially if physically able (but unsafe); the carer becomes like a prisoner. It is not just the patient who is unwell, but the whole family is affected. Need more support from sitting services and respite (but in patients own home where they feel safe)

Question 3

ANSWER:

Different cultural groups have different attitudes to caring for their elderly in general, not just with dementia.

Question 5

ANSWER:

My non-professional family members feel that medications for dementia are rumoured and kept secret. They feel these medications could have the biggest impact but that the public needs to know about them and who can or cannot have them, otherwise people think there's no treatment and nothing can be done, so don't seek help.

Question 6

ANSWER:

Depends on the individual. When discussing amongst the family there were mixed responses from would never want to know to want to know as early as possible.

Question 9

ANSWER:

people with dementia should be included not hidden away. Help for people with dementia tends to be in small clubs e.g at churches or hospitals. This is the wrong setting and medicalises the problem, as though should be a stigma and shut away.

Question 7

ANSWER:

People try to hide the dementia and apologise for it. They feel that nothing can be done and that the persons life is over as soon as they get it and should perhaps go into care.

Question 10

ANSWER:

Treating the patient as an individual is important, mainly social care and different individuals have various likes.

Question 12

ANSWER:

Makes relationships tense and angry. Carers feel guilty for losing temper with the patient.

Question 11

ANSWER:

Changes their identity on every level. Was it that this identity was there before and you didn't know about it? now that they lack inhibitions.

Question 13

ANSWER:

Like to think you can abide by the patients wishes from before. But at the time isn't so easy. Going along with their current wishes is often easier.

Question 15

ANSWER:

Depends on the stage of dementia and QOL. Simple treatments are ok but shouldn't be for resus and more invasive things should be decided case by case

Question 14

ANSWER:

The person taking responsibility for decisions should try to be impartial. Family

and NOK should be involved, but impartial advocates may play a role.

Question 16

ANSWER:

Welfare attorneys shouldn't be involved in making healthcare decisions, the health professionals should. The same person shouldn't have control over both health and money. Health professional is impartial and should have the vote.

Question 17

ANSWER:

Should play a big role. All people at early stage of dementia should be encouraged to make advance decisions

Question 19

ANSWER:

Should try to tell the truth at the start. If patient becoming distressed by the repeated telling of the truth is ok to tell white lies.

Question 21

ANSWER:

Blocking exit e.g. standing in way of danger ok. otherwise physical restraint is not acceptable

Question 22

ANSWER:

Usefulness of this would depend on level of education of the carers. Teaching or guidelines for carers on how to deal with certain situations eg behaviour management would be useful

Question 23

ANSWER:

Sound a really good idea. But likely to be expensive. Didn't know these technologies could be used for this purpose or where they are available.

Question 24

ANSWER:

Carers should have more support. If the patient wants to be cared for in their own home rather than going into care, carers should be supported financially so they can either give up work and be full time carer or can pay someone else to

care for the patient in their own home.

Question 25

ANSWER:

Often go with the carers decision. They can only do their best, and treating them as a whole not as seperate individuals

Question 27

ANSWER:

Needs of the well one over-ride the needs of the 'unwell' one with dementia. Always consider the impact of any decision on the other.

Question 28

ANSWER:

Too little information given. Should take information from families freely even if can't release information.

Question 29

ANSWER:

Prevention or cure

Question 30

ANSWER:

Shouldn't involve in research if lack capacity. Should only be permitted if consent given in an advance directive