

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.

Bromley PCT

QUESTIONS ANSWERED:

Q13

ANSWER:

It depends on how the lack of capacity is manifested. People can change their views over time and wherever possible family/friends should be consulted in conjunction with a multidisciplinary team.

Q14

ANSWER:

Every effort should be made to try and communicate with the person in the first instance, breaking down communication into manageable chunks where this is possible. The family and/or friends should be widely consulted in conjunction with health and social care professionals involved in the patient's care.

Q15

ANSWER:

There are concerns here where dementia has been inaccurately diagnosed and this diagnosis influences any further treatment decisions. It depends on the life-sustaining treatment under discussion. Staff feel that there is a difference between cardio-pulmonary resuscitation and other life sustaining treatment such as feeding and antibiotic therapy. There may be a tendency to 'overprotect' patients with dementia. A diagnosis of dementia should not automatically exclude patients from receiving life sustaining treatment.

Q16

ANSWER:

They should work as part of the whole multidisciplinary team, and not in isolation from it. Resolution of minor or more significant disagreements should be achieved by discussion and information gathering and possible by trying the person in the preferred environment with adequate support and rapid response services made available.

Q17

ANSWER:

It would depend on when the advance directive was made. People can change their minds, even those who are adamant at the time they make the advance directive. Staff felt that many people with dementia can live happily within the

confines of their condition. The families view should be taken into consideration, but guidance should be available to assist them with this.

Q18

ANSWER:

Staff feel that this has both helped and hindered caring for people with dementia. It has helped in that it has raised the profile and understanding of what it means to lack capacity and how this is no longer something for a single discipline to decide. The test for capacity is clearly described and it has helped with decision-making. It has hindered in the way that the quality of the decision depends upon those making the assessment, and some people still do not understand that capacity is decision specific. This can disempower people with dementia. The other concern is that people with dementia can fluctuate in their capacity dependent upon general health, medication, emotional state etc. It can prolong an inevitable process of seeking residential placement when the person believes they are completely safe to go home, but all the professionals believe this would not be in their best interests.

Q19

ANSWER:

Staff had mixed feelings about this. Some staff felt that it was not ethical to deliberately withhold the diagnosis of dementia from a patient who is asking 'what is wrong with me?'. It may be kinder in some circumstances to describe the condition symptomatically, and staff did not have a problem with holding the actual word 'dementia'. Some staff were very uncomfortable about medicating people without consent, but others had witnessed positive changes in mood and behaviour in patients which would seem to be in the best interests of the patient. Wherever possible, the choice should be given, and people with dementia should not be treated like children or patronised.

Q20

ANSWER:

Generally it was felt that people err on the side of caution and do not always allow people to take risks, even if their history and family suggested that they had been risk takers all their adult life. Professionals were particularly guilty of this and this also reflected whether staff had positive or negative clinical experiences of working with people with dementia.

Q21

ANSWER:

Yes, staff believed that a gentle form of restraint could be used cautiously and in consultation with the whole team including friends and family members. This may be for the safety of other patients, or possible to encourage the patient to

attend important hospital appointments. Constraints could be wheel chair seat belts, but always explaining the reasons why. Any decision about using a restraint, should be individual to a particular patient at a particular time and not a blanket decision.

Q22

ANSWER:

Yes. Via an independent source, i.e. it would not be appropriate for the clinical team looking after a person with dementia to provide this education to a carer in an emotionally charged environment. It should be provided by an independent advocate.

Q23

ANSWER:

Telecare was generally thought to be useful but with some concerns expressed over possible invasions of privacy. Tagging and tracking devices were not thought to be ethical. It is important that new technologies should not be applied too mechanistically, reducing the human approach.

Q24

ANSWER:

This provoked a huge debate about the responsibilities of the state. The ethical basis would seem to be that in a caring society we should take care of vulnerable groups. However, some felt that it was right and proper that a person with dementia should be asked to use funds from a property they owned but were no longer able to live in to fund their care. This may result in their being a greater choice for them.