

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.

Professor June Andrews
Director
The Dementia Services Development Centre (DSDC)
University of Stirling

Q1

The greatest impacts from dementia are

- The personal desolation for the person and the family
- The fiscal consequences for our society
- The moral degradation caused by poorly educated staff working in under resourced services, which reflect the low status of older people and vulnerable people with mental health problems in our society

The support needed is

- Education for front line staff
- Information and education for carers
- Redesign of services to provide a more joined up system

Q2

The ethical issues that are often brought to my attention include

- Neglect of personal care needs and basic requirements such as food and drink "explained" by poor staffing levels and staff education and bad organisation in institutions
- Failure to respect legal rights of people with dementia by assuming no need for consent for care and interventions
- Multiple forms of abuse, which go unreported or unrecognised

Q3

I have no particular knowledge of this

Q4

The questions that arise come mainly from the absence of awareness in the dominant culture in the carers, of the specific culture of the cared for.

Q5

The most significant scientific developments are

- From the science of design and technology, assistive technology devices to maintain independence and reduce institutionalisation

- From the science of education, methods of teaching values and standards to staff with high turnover and low previous education
- From the science of pharmacology, methods of measuring the effectiveness of compounds which focus on the subjective outcome for the patient and carer, rather than quasi-objective measures that are currently used.

Q6

The diagnosis should be made and communicated at the earliest possible opportunity.

Q7

Society has a very negative perception of “dementia”, equating it with decay, shabbiness, and ultimately horror. I say this while reflecting on the response of everyone from taxi-drivers to relatives when I tell them that I am a professor in this subject. People agonise over whether there is a more attractive set of words to describe what happens in my building. But it is getting better.

Q8

Stigma stops people recommending dementia care as a career. Shame about some of the symptoms stops people from seeking help. The dishonour in which we hold older people in our society, and the fact that dementia is seen as synonymous with “senility” means that we joke about dementia in a way that we would not about any other fatal diagnosis.

Q9

Yes. Some ways of doing this include

- Make the public more generally aware of the problems of the person with dementia so that they are not afraid to help and have skills to help (for illustration, we like to help blind people across the road, and now we know better how to do it...don't grab, but ask, and introduce yourself etc)
- Encourage people in the early stages of dementia to speak out about it, identify themselves, and demonstrate that there is a lot of life while living with dementia
- Through children and young people, who are astonishingly tolerant, teach respect for people with cognitive impairment
- Make sure that people with dementia provide the teaching for professionals
- Make the design of public buildings and social housing “dementia friendly” (which is inexpensive and aesthetically pleasing)

Q10

It is no longer as helpful as it once was. It is now "jargon". It was an inspirational idea from Tom Kitwood when he was relatively young and he would have developed his thinking since then if he had been spared. His brilliant idea from then is now abused and has been exhausted by overuse.

Q11

Because I think that our identity is constantly changing I don't think that my answer to this question would be interesting.

Q12

The implications of changes in mood and behaviour are

- The family and other carers may have to take a pragmatic view of the values and wishes expressed before the onset of dementia in the light of changes that have taken place.
- There is a pleasing sense of "honouring" the wishes of a person with dementia by treating them as they would have wished when they are not longer (apparently) aware or (apparently) able to express or change their wishes, which is as much about maintaining the sense of humanity of the survivors, as an action towards the patient.
- The relationships and ties remain the same, but there are good reasons for changing how they are expressed, in the interest of the surviving family

Q13

Yes

Q14

A careful one

Q15

A diagnosis should influence the decisions made in the same way that any fatal disease affecting quality of life for the patient should.

Q16 No response

Q17

Advance directives should be followed as far as is practical, and people should be encouraged to make them

Q18 No response

Q19

It is permissible to lie to a person with dementia in exactly the same proportion as it is permissible to tell a lie to anyone else.

Q20

People err far too much on the side of caution. Freedom of action and risks should be balanced as best we can, and we all have to take moral responsibility for our actions, within managed systems.

Q21

Restraint should be permissible but only as a last resort and the lightest possible restraint, for the shortest possible time and reviewed and reported on regularly. The biggest hindrance is over cautious staff and over anxious relatives.

Q22

Ethical education is required.

- basic ethical education in schools, colleges or university professional education
- short dementia specific ethical education during induction programmes, during which the legal position, the organisations procedural policies, and how to make and record decisions are covered
- education requirement on decision making and ethics for managers of systems

Q23

Issues

- lack knowledge of what there is and what it can do means that some patients don't get a choice
- lack of resource, or fear that it will "replace" human care means some patients don't get a choice
- overuse of technology can effectively constitute unrecorded and unreviewed restraint for patients

Not used because

- not available, not affordable, not known about, seem too risky, too complicated, too new, too experimental, stigma associated with crime, impersonal
- not asking people with dementia what they think (they often are more open to it than their carers)

Q24

Duty owed

- to provide medical and social care based on need and free at the point of delivery
- to regard the person with dementia and their carers as a “unit”

Q25

The more vulnerable party should be protected by the state.

Q26

Health and social care professionals should be trained in mediation or have access to mediators, for resolving conflicts of interest.

Ethical dilemmas might include

- Should I tell the family that this care setting/programme is substandard, or reassure them that it is good as it is the best I can offer?
- Should I allow this person with dementia privately to have a sexual relationship, or should I tell the family to allow them to decide to forbid it?
- Should I respond to this carer’s view that they are being abused by the patient, or is the patient my only responsibility?
- Should I respond to an apparent abuse of the patient by the carer, or do I remain silent, as the alternative institution is probably unpleasant and not what the patient would have wanted?
- Should I respond assertively to this medical emergency in a person with dementia simply because the family demand it?

Q27

The needs of all the people involved need to be taken into account in every situation. You may decide that some needs of some of the parties are more relevant or less relevant. You may also decide to more heavily weight the needs of the more vulnerable person, because they have fewer opportunities.

Q28

Patient confidentiality in our system has been distorted into a charter for secrecy, when staff feel confident to deny even useful or helpful information that would support the patient’s care to other professionals or relatives. And when really useful information has not been communicated due to lack of insight or attention to detail, people fall back on confidentiality as justification for their failure to communicate. They are not prepared to make the effort to judge carefully, take a calculated risk, and record their judgement and defend it, but

would rather avoid the issue. The same people, who closely guard secrets, are often not so particular about consent. In each case they are taking a line of least effort to themselves.

Q29

The priority for research must be

- Non pharmacological interventions for people with dementia
- Interventions that support carers in the community

Q30

- Not having capacity to consent to research should not automatically exclude the subject, and the research should be permitted, depending on the intrusiveness of the research intervention. The safeguard should be in the form of research ethics guidance for the specific programme devised by a group including people with dementia and not dominated by clinicians.
- This would be less of a problem if we all signed advance directives allowing ourselves to be involved in research if capacity ever is lost

Q31

- I do not know

Q32

This has been extremely comprehensive. Thank you for raising this is