

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.

Age Concern Leeds

QUESTIONS ANSWERED:

Q3

ANSWER:

From our work at Age Concern Leeds, we would always be cautious about assuming that BME groups require very different services. In particular, there is a danger of assuming that some groups 'look after themselves' and have stronger family structures, so do not welcome outside help. It is likely to be harder to break down barriers to accessing new service and resistance present differently, but service providers must look beyond the superficial and 'official' responses in order to understand and provide better help.

Q4

ANSWER:

Apart from obvious factors like religion, language, diet, and related issues such as gender sensitivity and roles, timings (observing religious holidays and observances), or location and building layout (where are the toilets facing in day-centres? is there a prayer-room space?), there can be absolute conceptual difficulties. For example, many non-European languages have no words equivalent to 'carer', 'learning disability', or for relatively common conditions such as 'claustrophobia', so that offering help or diagnosing need can be very difficult at the outset. Much greater resources need to be put into tailoring services that will address these problems, in terms of staff recruitment and training, language support, appropriate adaptations for premises, etc.

Q6

ANSWER:

Diagnosis should be communicated as soon as possible, with as much accompanying information as possible. There may be relatively exceptional circumstances such as the dementia already being very advanced, or combined with serious learning disability, or with other end-stage terminal illness, where it may not be helpful or productive for the patient to be told. The presumption of early information of course again calls for an adequate level of resourcing to supply both information and (in the broadest sense) counselling to support the patient and family/friends/carers.

Q8

ANSWER:

(Questions 8 and 9 taken together) I have some personal concern about the

'mental health' label on dementia, as the condition is a degenerative brain disease, and 'mental health' may imply curability or even willful refusal to accept treatment or counselling if treatment is not effective. (Although clearly some psychological therapies can be helpful in some cases.) Early-onset dementia sufferer Christine Bryden (in Elizabeth MacKinlay: Ageing, Disability and Spirituality, Jessica Kingsley 2008) refers to 'brain damage', which is a better - and self-selected - description. The combined stigmas of ageism, mental health, intellectual impairment and physical disability must mean dementia just about has the lot! However, education about the ageing society, and awareness of high-profile sufferers, may mean an improvement in attractiveness to research.

Q9

ANSWER:

Once again, the resource issue is key. Support to utilise other services must be provided if both dementia sufferers and others are to make best use of specialist and ordinary facilities. In communities where people have known each other for a long time and aged together, do not under-estimate the importance of peer support to 'contain' the problem. Other older people can be very supportive and helpful to someone they perceive as struggling - eg reminding and reassuring them about keys, glasses, coat, people, appointments... The value of ordinary, long-standing social groups and informal support networks can be immense, but require time to develop.

Q10

ANSWER:

The notion of person-centred care is axiomatically good: how else should care be provided?! However, manifestations such as 'personal budgets' and 'self-directed support' for health or social care can be burdensome for patients and carers/families, and require (properly resourced) support to manage. There is considerable danger that such developments will lead to cutbacks, unregulated care providers, and lack of attention to the person's changing needs.

Q11

ANSWER:

The identity of the person is not changed, but their emotional, psychological, and relational responses may be. This may not always be for the worse; it may throw up issues which have been long suppressed (such as sexuality); or it may exacerbate personality traits or (apparent) belief systems. (For example, someone may claim religious reasons for refusing treatment, when the real reason may be fear.)

Q12

ANSWER:

(Also Q13) Difficulties from issues outlined in question 11 are self-evident. Families and friends may be shocked and rejecting because of changes in reaction or traits revealed. The importance of knowing (as fully and intelligently as possible) what the person was like before the onset is crucial. Because this may not always be possible (see Q2) decisions and understanding may also wish to have recourse to 'experts' (eg religious ministers) who may have an influential understanding (from the patient's point of view) of reasons why certain actions may be taken, and what exceptions are permissible (eg regarding refusal of treatments).

Q14

ANSWER:

Since many report dementia to be episodic, with patients showing more awareness at some times than others, use should be made of the lucid moments. However, medical and care discussions should not dominate the person's life! Continuing to respect the person 'outside' the dementia is important in understanding their wishes and tendencies too.

Q16

ANSWER:

Again this service requires proper resourcing if it is to be effective. There is no formula for resolving differences; each should be taken individually. Knowing the person, consulting family and friends, understanding the background to beliefs, are all important in understanding what the 'best interests' are.

Q17

ANSWER:

See also 6, 11, 12, 16. Patients should be provided with adequate information in advance, including the likelihood of change, to avoid them making draconian decisions out of fear or ignorance of the development of the condition. Reasons for particular decisions should be investigated, if possible and with sensitivity, if and when advance directives are made. Have they been made out of fear? for religious reasons? as a result of coercion?

Q19

ANSWER:

There can be no formula for this. Everything depends on the situation under discussion, the person, their preferences and values, and their needs. Crucially, the over-riding importance is to respect and relate to the person themselves. For example, a (paid) carer of a man with Alzheimer's persuaded him to attend the day-centre (which he had vehemently resisted) by engaging him in conversation about his previous work, about which he was still lucid. She then invited him to visit her workplace (the day centre). Once there, the man enjoyed it, met new

people, and became a regular supporter. Whilst the carer had 'lied', she had respected the man's interests, values, and contribution - she had valued his conversation about work. 'Lying' to a woman who refused breakfast because she believed she had to get her children ready for school would be similar, in respecting her sense of self as a mother. Perhaps similarly, it would be compassionate to gloss over the whereabouts of a deceased partner, but perhaps appropriate to make use of 'lucid moments' to reflect the truth and allow grieving.

Q22

ANSWER:

Work has been done at Bradford University on this issue. Family carers, unlike professionals, have no training or framework to fall back on, but greatly appreciate the opportunity to discuss, with suitably qualified and sympathetic people, the dilemmas and unanswered questions they face all the time. This need not be formal 'training', but could greatly increase confidence and provide reassurance that family/unpaid carers mostly do the right thing instinctively, through thorough knowledge of the person. And where they do not, discussion of options, reasons and principles is likely to help.

Q23

ANSWER:

There is great fear of the 'surveillance society', and possibly genuine concern that people with dementia or older carers may not understand or use the technology effectively. It may also be dehumanising and frightening: how would a confused person react to a disembodied voice from the wall asking why they are opening the door?! Whilst some may also engender hilarity (eg the bed sensor calls the ambulance because the person has woken in the night, made a cup of tea, let in the cat, switched on the TV and not returned to bed in time!) they can be genuinely freeing (eg tracking devices so doors do not have to be locked) if backed up by human presence, and if possible explained to the user in friendly terms.

Q24

ANSWER:

Dis/ability or impairment, whether mental or physical, does not make a person any less valuable to society, family, friends, or the local community. No-one is fully 'independent': we are all inter-dependent on a complex web of tangible and intangible, known and unknown relationships. Therefore the state 'owes' the fullest possible experience of life to dementia sufferers and cares as to anyone else. In an ideal world, we would wish to see support, including personal and domestic care, transport, adaptations (including technology) available for daily living, either at home or in residential care. Day services away from home, day and residential respite opportunities, and residential care should offer enjoyable,

stimulating and varied activities, whether specialist or by joining in the mainstream, with support. Professionals involved should have time to get to know patients and families thoroughly, including wider and non-local family members or friends, to build up a full picture of the person. Specialist care, advice and help should be available where necessary, including cultural and religious. And the person should not be turned into a medical case where the issue of dementia dominates each situation!

Q27

ANSWER:

The needs of carers and families, especially partners, are enormously important. The primacy of keeping someone in their own home should be challenged if this threatens the wellbeing of others, and the relationship with the dementia sufferer. Naturally the alternatives should be as enjoyable and flexible as possible, which is again a resource issue! The quality of life, particularly of an older carer, is as important as that of the 'patient'. They should not have to sacrifice their later years to the exhausting and often apparently thankless task of caring. Early education about other options, to both/all parties, would help make these decisions easier and less prone to conflict. In our experience at Age Concern Leeds of providing carers' services, we have observed that it is often the least 'successful', least assertive member of the family who is left to do the caring, and can suffer mental health problems as a result. More attention (again, resource-intensive) to the wider family circumstance would put the caring relationships into perspective and ease decisions for all concerned.

Q25

ANSWER:

See 16. Note also that demands from the cared-for person can be unreasonable, but a family carer may be reluctant to admit this. In our care to prevent abuse of the 'patient', we must not forget that abuse can be directed towards the carer too, and a diagnosis of dementia does not mean that the person cannot (continue to?) be exacting, hurtful, or even spiteful towards their partner or family.

Q28

ANSWER:

In our organisational experience at Age Concern Leeds, we find there is a tendency to withhold too much information on the grounds of confidentiality, leading to lack of understanding from family carers, and reduced ability to cope, especially in mental health diagnoses. Obviously privacy and dignity are important - and things should not be discussed as if the patient were not there, or in front of others - but this is not the same as sharing information to enable understanding and appropriate care. As a rule of thumb, if paid carers are given

the information, why not family?

Q32

ANSWER:

See 24 for over-arching reasons. In an increasingly atomised society, facing an increase in both older people and single people living alone, the essential requirement (mentioned in many responses above) to know, understand and respect the person so as to make appropriate decisions and responses will become more and more difficult. Older people may live many miles away from family members and have lost contact with friends. It is hard to know how to overcome this problem, other than by very early preventative 'services', such as informal social groups, where people can get to know one another before problems set in. Resourcing is absolutely everything. In a climate of cutbacks, veiled cutbacks (such as personalised budgets), and increasing burdens on the voluntary sector to both be more professional and more competitive, it is hard to see how the levels of attention and consistency required for excellent dementia care can be achieved. Dementia care is in many respects no different from other forms of care, especially for the needs of later life. The greatest ethical issue of all is how much of a priority does society make this?