

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.

Barbara Pointon

Q1

Behavioural disturbances, loss of speech, the physical breakdown in severe dementia, the sheer length of the illness and the high level of vigilance cause huge impact on either the patient, their immediate family or both. The sheer cost of dementia care has an impact upon individuals and society, together with the stigma surrounding dementia.

Q2

Making decisions on behalf of people who have lost mental capacity; issues around risk versus quality of life; balancing patient and carer's needs; validity of advance directives in changed circumstances; family carers seen as "interfering relative" rather than "partner in care"; extending life by artificial intervention or not; knowing when to "let go".

Q5

Clinically, stem cell research and vaccination. In terms of care, that anti-psychotics are not always the right response to perplexing or annoying behaviours and that a person's history holds vital information.

Q6

Early diagnosis and communication of it is vital. People have learned to accept other life-threatening diagnoses, provided they know that support and treatment is available, and it should be the same for dementia. Early diagnosis allows for planning ahead while the person still has their capacity to do so, taking up long-promised holidays while you still can, putting affairs in order, considering stopping driving, the introduction of drugs to allow a better function for longer (*pace* NICE) and most importantly, protecting the family relationships. When relatives and friends understand the reason for changes in a person (e.g. no longer being able to do something they've always done) then they can make allowances and not become impatient or angry with them. We all have a right to know about the state of our bodies and minds, but if there are good reasons why some people don't want to be told then that should be respected, but it won't half make life difficult later on! (e.g. medication may be refused because they believe nothing is wrong with them).

Q7/8

Ignorance breeds fear (compare cancer in the 1950s). Fear breeds stigma. Society still perceives it as a disease of old age, a particularly nasty one at that, for which nothing can be done. There needs to be a national Public Health Campaign to inform, educate and reassure that help and support is available; but at the same time not to whitewash – e.g. dementias are terminal illnesses.

Q9.

Yes. More acceptance and flexibility in dealing with people with dementia in public places (compare the long but successful campaign for physical disability access). In this case it would be around understanding why people with dementia can become messy with their food in restaurants; that they are likely to say things out loud in theatres and concerts; that they may need to pace about on trains; that lavatories should be clearly signed. Family carers should try and accept help from neighbours more readily (there is a tendency to shut people away or to believe you can do it all yourself) – when neighbours offered to form a rota to take my husband for a walk every day I jumped at it!

Q10

Yes, it is vital. Dementia affects the whole person: physically, mentally, psychologically, emotionally, socially, sensorily and spiritually. Each person's dementia is unique, according to the pattern of damage in the brain, as is their response to the illness, and so is the setting of their care. One-size-fits-all type of care will not do. In addition, people with dementia remain true to themselves and it is vital to learn about their past history, which often explains bizarre behaviour (see; Graham Stokes – *And Still the Music Plays*). Good dementia care is holistic care.

Q11

See Q10. No, it is not true. The outer person the world values (skills, talents, social interaction, cognition, abstract thinking, sense of humour, physical functions etc) gradually gets shot away by dementia, but the essence of the person remains, needs cherishing, and is there to the end. *(I will append a diagram ordinary people find useful in comprehending the ravages of dementia)*

Q12

It can create isolation for both the person with dementia and their carer. In our case, it sorted out family and friends. True friends stayed in contact, others simply fell away. My ex-daughter-in-law refused to bring our first baby grandchild to see us because her Health Visitor had warned her that my husband might harm the baby. The professional ignorance is breathtaking. I found it hard when my husband blamed me for everything, including his dementia. He became aggressive towards me, but I reckon with hindsight that it was because I had overstepped the fine line between caring and controlling. I wish I'd known then what I know now about avoiding and dealing with perplexing behaviours. I learned the very hard way to Go With the Flow, however irrational it seems. And I don't hold with the excuse some family and friends gave for not visiting: "because he doesn't know who I am and he can't talk". The person with dementia still appreciates special attention, human contact, a friendly face and voice - and the carer would like a bit of company too.

Q13

I reckon we must go with the person as they are now. If they can't enter our world, we must enter theirs, however different it is and enjoy it with them. My

husband used to be a good amateur artist, so when asked, I said at daycare that he liked painting. But, unknown to me, his Alzheimer's had seriously affected the visuo-spatial area of his brain. He knew his painting was rubbish. He would come home, tear it up and throw it into the bin and I had to contend with his anger for the rest of the day. His new hobby was walking about, collecting stones, but that was never on the daycare menu.

Q14

A case by case decision. But I thought that the presumption must be that they have capacity, even if only just, unless proved otherwise. And the other difficulty is that capacity can vary from day to day– my husband's diary reveals this, with entries like "Not a good day", "Muddle-headed morning and afternoon" , "Mental fog...just didn't want to talk to anyone" interspersed with "Excellent day to bring me out of meaningless torpor".....

There are so many variables; we must just try to be as fair as possible and be guided by what is in the patient's best interests (as perceived by those nearest and dearest) at that particular period and not rely on snapshots for decisions.

Q15

With no official advance directive in our case, I was guided by an entry in my husband's diary "So it's Alzheimer's. When the end comes, I hope it's not too messy". Way back, the GP and I constructed a letter to lie on his file saying that when a terminal stage is reached, no aggressive interventions except for a syringe driver to alleviate terminal pain, epileptic activity or distress should be undertaken. In his last chest infection, his swallowing disappeared altogether, he appeared weary and wanting to let go, and I had to decide whether to admit him to hospital to continue the antibiotic treatment intravenously. I decided it was in his best interests not to be moved to a terrifyingly noisy new environment, but let nature take its course at home, and that would be true to his diary entry and the letter on the file. But, despite knowing that it was the right one, it was still a terrible decision to have to take on behalf of another human being and the responsibility weighed heavily.

Q16

A welfare attorney is usually chosen and appointed by the patient because they are believed to know them best. They must therefore be given due weight, unless there is evidence that the attorney has not been in contact for some considerable time. If the issue in dispute is minor, then go with the attorney's view; if it is significant, then a neutral third party should be brought in to try and resolve it. It also depends on how well the health professional knows the patient – e.g. there is a difference between the opinion of a long-standing GP or nurse and a nursing assessment made on one visit by a relative stranger.

Q17

People should be encouraged to make one, and for it to be a factor in the equation, but to understand that the view of the world they have now may be quite different ten years down the line. It is also ridiculous that particular

treatments must be specified – how do ordinary people have the detailed clinical information, and who knows what’s in the pipeline for the future?

Q18

I think it prevents health professionals from making unilateral decisions without consulting and taking into account the views of family carers. In hospital, the next of kin rule needs to be expanded to take in civil partners, including homosexual partnerships, and in the case of elderly people with no family ties left, the views of a “significant other” in their lives.

Q19

Yes. Many people with dementia time-travel backwards and are in a different time, even place. If an elderly person in a care home asks, “Is my mother coming to see me?” the ardent keeper of the truth would reply, “No –your mother died ages ago” and the result would be shock and grief all over again, every time it’s asked. Knowing that, you have to take evasive action instead, and reply along the lines of, “Tell me about your mother”. My husband used to say that there were little men with long green noses in the garden telling him what to do. I had to suppress my natural instinct of saying “Don’t be silly – there’s no-one there” because he would then think he was really going mad. So I would reply, “What are they telling you to do?” When was it a sin to prevent hurt or distress?

Q20

Some staff in carehomes and hospitals are almost paranoid about risk. We can’t wrap people up in cotton wool – no one can be risk-free. Risk needs to be managed, not prevented altogether. For fear of risks, too many people with dementia have a poorer quality of life. For example, in a hospital respite setting, my husband was overmedicated so that he would not walk about and be a nuisance. He was miserably and unnecessarily confined to bed and a wheelchair for the convenience of the staff. I took in a man who could walk 10 miles and it took ages for the medication to wear off and for him to walk again.

Q21

I am in favour of electronic tagging to give the person their freedom to walk in the neighbourhood, allowing the carer to know which way they had gone, to find them if necessary and prevent them from getting distressed and lost. This is not an infringement of their human rights, but a freedom to walk where and when they want, whilst reducing risk to them and also the level of anxiety for family carers which can be caused by hours of searching in the dark or the rain. I am not in favour of physical or chemical restraint.

Q22

Yes. Via discussion in Alzheimer Society carers’ support groups or with a dementia care adviser.

Q23

See 21. I can see why some people are concerned by the method by which satellite surveillance is given and the possibility of it being intercepted by unscrupulous people. If an elderly person with dementia lives with their family, they would naturally be watched and supervised as part of the care and for peace of mind on everyone's part. So it kind of makes sense that if they live some way away, a camera can help to check things out. But it shouldn't be used as a reason not to visit and give face to face care as well. It would also depend on the level of dementia: whether the person with dementia would welcome the extra security it could give, or whether they would feel they were being spied on, or whether they can't understand and don't really care one way or the other, but the family carer would feel less stressed if it were in place. No black and white answers!

Q24

The State has a moral duty of care and protection towards its most vulnerable citizens. But it gets twitchy when it costs. Free care may be unobtainable, but the caring charges should be more transparent and fair. And because dementia is caused by diseases which create organic and chemical changes in the brain; it could be argued that its care is healthcare and therefore free.

The State is also in debt to family carers. Family carers save the State £87 billion annually – almost as much as the NHS Budget. The least they should be given in return is a respectable Carer's Allowance (which should not cease once carers turn 60 or 65) and free respite/ planned breaks in proportion to the number of hours per week they spend in caring. For carers of dementia it is a 24/7 job.

Q25

Usually, what is best in terms of care for the person with dementia – i.e. that which maintains or improves quality of life – is also best for the carer. If a conflict should arise, it would be useful to have the issue resolved with the help of a dementia care adviser, carer's support worker, health professional or neutral advocacy. Sometimes you just have to bite the bullet, and tip the scales in favour of the carer, remembering that if the carer goes down, the whole ship goes down with them. I used to send my husband to respite, even though he came back in a worse physical and psychological state than when he went away, because I just had to have that break from 24/7 caring. I felt awful about it, that my needs were taking precedent over his. That dilemma was resolved by lateral thinking – people with dementia reach a point when they are frightened of going anywhere outside their familiar surroundings – so we devised respite care through replacement of me at home with a regular and therefore familiar careworker. He was well cared-for, and I got my break.

Q26

Health professionals see and support both the person with dementia and their carer. I valued their advice when dilemmas arose (and I think they took the same view about the ship going down as in Q25!).

Q27/28

Health and social care professionals also took into account that we were a couple, that the quality of our lives were intertwined and so they discussed many aspects of my husband's health and social needs with me. However, I know of situations, for example where a wife, physically abused by her demented husband, went to the GP to ask for advice on managing this behaviour, but was told by the GP that he could not discuss her husband's condition with her because of medical confidentiality. Apart from this being downright callous, confidentiality is not as absolute in law as some think. Actions and advice can be in the best interests of both patient and carer when pertinent medical information is freely exchanged.

Q28

Knowing how much information to share depends on individuals and the situation. Some carers don't want to know details. Other carers, like me, feel that the more they know and understand, the better the care and support they can offer. I wish someone had told me about the later stages of Alzheimer's at the beginning. If I'd known then that my husband could lose his speech and all his mobility I would have made sure that we had a whale of a time while we still could. That would have been to the benefit of both of us.

Q29

Discovering causes and cures; promoting good care practices. While there is still little hope of the former, then I would think funding allocation should be on a 2:1 basis. When funding for dementia becomes equal to that of cancer (if only!), then decisions about how to allocate may not be quite so fraught.

Q30

While he still had capacity, my husband consented to take part in lots of research based at our local teaching hospital. But he actually became traumatised by over-testing (which tended to emphasise what he couldn't do and undermined his confidence further) and a behavioural psychologist recommended he should stop. That would be one safeguard, whether the person had consented or not. He was also on an early clinical trial of Exelon, did well on the low dose, but could not tolerate a higher dose and produced side-effects of nausea and epileptic seizures. I asked if he could be taken off for a few months, or return to the lower dose to see whether it was the drug producing the seizures, or if it was the next twist in the dementia. Not possible. He had to withdraw completely from the trial, and within 3 or 4 weeks could no longer wash himself. Surely the interests of the patient, to stay on the lower dose of the drug, should take precedence over conforming to trial protocol, for even though his experience would have been discounted in the trial results, it could have provided a footnote?. We didn't have the experience of contributing to research after he had lost mental capacity, so I can't comment further.

Q31

I feel that limited, necessary use of primates in brain research is justified. The brain is highly complex and controls everything we do or think – how else are procedures or pharmaceutical products to be tested except on living, sentient beings? But the standard of conditions in which the animals are kept should be good and transparently so.

Q32

I would like to comment on the unethical manner patients with severe dementia are treated in some institutional settings. Because they are mute and immobile, they are said to be “no trouble now” and are left for long stretches of time confined to bed, with the same viewpoint all day and with minimum of human contact except for essential care tasks. They are being treated as less than a person, yet they still have sensory, emotional and spiritual needs which are being neglected. We need to look at ethics in palliative care in severe dementia.