

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.

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Q1

I think that for the person with dementia the greatest impact comes from the loss of their previous role, whatever that might have been. If they have to give up their job for instance, or the things in the home for which they were always responsible, looking after finances perhaps. In my mother's case it was having to give up her voluntary work - she had been a Samaritan for over 20 years. Some combination of their symptoms, which will vary considerably from person to person, renders them no longer to be relied upon.

For families and family carers, I think it is the inability to make decisions which can have greatest impact. If the person with dementia has expressed their wishes about such things as who they would want to care for them; where they would like to be looked after; what sort of treatments would they want to receive in the event of infections; would they want to be resuscitated if they suffered a stroke on top of the dementia; and so on, then at least there is a starting point. However, I am far from convinced that wishes made in good health can necessarily be relied on to still be held when health circumstances change. So I think there is still tremendous pressure on families/carers to wonder if they are doing the right thing.

The inability to face reality also impacts greatly on families/carers, and can be linked to the above. My own mother always blanked any attempts to raise certain questions about her future - it just was not going to happen. I don't know how much of this behaviour was within her control, I do know it was very stressful for me and has sometimes led to feelings of resentment on my part.

Support needs to be tailored to the specific needs of the individual and their carer. For much of this it is essential that supporters are specifically trained in dementia issues. In my own case, professionals tried to raise issues such as where my mother would want to live, but were unable to get her to face the reality of her situation.

Q2

Further to the above, I have faced difficulties with issues such as where my mother should live. As her only child, and living some 300 miles distant, I felt my only choice was to bring her to live with me. I know she did not want to leave her flat or the town where she had lived all her life. Those giving support at her at home felt they had done all they could and that she was at risk. (I did feel to a certain extent there was some emotional blackmail there). But I thought that if she went into residential care in her home town she would have

very few visitors, as her sisters had all died and friends were all elderly, days would be long and life grim.

Dementia seems to lead its sufferers into a place where they become the centre of their world and lose awareness of other people and their lives.

Q3

I have no personal knowledge of different understandings of dementia among other groups. Traditionally, I have understood that some ethnic groups, particularly Asian and Oriental, have stronger extended families. One might therefore assume that they would embrace and absorb a family member with dementia more easily than those of us with smaller and more fragmented family structures.

Q4

Clearly there needs to be strong awareness of cultural difference, but on a personal level, not the gross generalisations that can pass for knowledge. However, everyone receiving care is an individual and there can be as many differences between people of apparently the same culture, as between those of different cultures.

Local leaders of minority cultural groups should be consulted at the earliest possible opportunity if difficulties are anticipated in issues such as the use of male carers with female residents. If a town has a multi-cultural association that would be a good first port of call.

Q5

Focus tends to be on the possibilities of drugs to slow down the development of dementia, but while these are being developed many sufferers will live and die with their dementia. They deserve to benefit from greater understandings of dementia which seem to take forever to percolate through to the coal face. For instance, it must by now be well known that those with dementia frequently need encouragement to drink. Yet still drinks are put beside people without a word only to be removed, untouched half an hour later. The dementia patient may not know what the word drink means, nor recognise the object, yet little or no help is offered.

Q6

Over the last 30 years or so, this same road about diagnosis has been travelled with reference to cancer. It does look as though most people are able to find strength and a way to deal with diagnoses of cancer, but there will be others for

whom a different way is best. It is never right to assume there is only one way of doing things. I do not, however, like the thought of some people knowing details of a diagnosis, but the person themselves being unaware - I feel the diagnosis 'belongs' to the person with the illness. Hopefully, with much more openness about dementia, which is bound to happen given the demographics, we will all consider the possibility for ourselves and only present for diagnosis when the seed has been sown.

Q7

Society perceives dementia is a very negative way on the whole. Our present emphasis on 'quality of life' is, I feel, responsible for this. (I'd be interested who coined this phrase?) But alongside others in society, sufferers of mental illnesses for example, and even older people generally, those with dementia should be valued for what they are, the person within, rather than what they can do. It is another aspect of the triumph of material over spiritual values. Openness, honesty and greater prevalence will slowly remove the fear which surrounds dementia. But it will be a long process as long as we are obsessed with control in every area of our lives. Ultimately, control is not in our hands. In an interview shortly before his death, Humphrey Lyttleton observed that "Life finds its own level". I think this can be a valuable mantra for carers. But I fervently hope that euthanasia is not offered as the solution to dementia, in the way that abortion is now offered as the solution to a baby who is in some way less than society's definition of 'perfect'.

Q8

Sadly, yes I think so, but often largely born of ignorance. So that the more everyday experience people have of those with dementia, hopefully the stigma will decrease. But again, as above, another long process, probably only achieved by the drip-drip effect. Alzheimer Scotland is doing some useful work in schools so that children will not be afraid if their grannies or granddads have the illness.

Q9

Yes of course, by not hiding people away. As more people with dementia are remaining in their own homes they should become more visible. I know it's not easy, but I would hope carers would continue to take their 'charges' out into the community as much as possible. Most people seem to react kindly (at least to my face!) if my mother tries to connect with their small children, for example, if we are shopping. People with dementia and their carers should be included in the community events that are organised for the over 60s, Christmas parties, for example.

Q10

My first response to this question is to ask what other sort of care can there be? How can any care, worthy of the name, be other than centred upon the individual?

It does place greater demands on any carers. Family carers should be well acquainted with the individual, they will at least have their own picture of him/her. Professional carers will need time to learn about the person. Memory books can be helpful here, and can also be therapeutic/cathartic for the family member who prepares them. Of course, this means that time must be built in to the carer's duties so that they can give due attention to any material that enlarges their view of those they care for. And this is where things easily fall down. I doubt that the memory book I have sent in with my mother to respite care has been read by staff or offered to visitors.

As to previously expressed versus current (apparent) wishes - this is a minefield! I would not wish to treat any previously expressed wish as strictly binding, especially as such views are often expressed in isolation. On the other hand, if the individual is unable to express any choice now, and none seems clear from their behaviour, then their previous view is all there is to go on. All I would say, if things really come to the crunch, is that I would err on the side of life.

Q11

My own experience tells me that it is not the case that a person's identity is changed by dementia. It may be, of course, that different types of dementia lead to different answers to this question. And different relationships too. I've heard professionals tell caring wives that "He's not the man you married". How do they know, I wonder. But perhaps the parent-child relationship is different. There was no time when your parent wasn't your parent, and no element of choice in the matter.

We all change our behaviours at certain times in our lives, some much more than others, but our essence doesn't change. If we know someone really well I think their essence remains apparent to us. It's probably people not so close who feel things have changed more, and that the person with dementia has lost their identity, because they have lost the bit that the acquaintance knew.

Q12

Changes in mood and/or behaviour often have radical implications for relationships, dementia or no dementia! But I don't think dementia absolves

one of obligations willingly undertaken prior to its onset. Nor should other's views be disrespected because they can no longer express them.

Q13

If people are able to express themselves currently, then they must be allowed to change their minds from previously expressed feelings, if their current view is expressed consistently. If, on the other hand, we have only the previously expressed wishes to go on, then those should probably be allowed to stand. Now there is the legislation, it should be made clear to anyone now expressing views to be acted upon at a later date, that these will be binding if totally capacity is lost.

Q14

Judging borderline cases like these must take into account the magnitude and significance of the decision. They should not be rushed into, unless there is a real emergency. If professionals disagree, then go with the individual themselves, but don't leave carers to pick up the pieces alone.

Q15

When a person who has dementia contracts some other ailment, then on the whole I believe the other ailment should be treated just as it would be in a person without dementia. Otherwise, the implication is that life with dementia is not worth living, and a chest infection, for instance, is a fortunate development since we cannot openly advocate euthanasia. Err on the side of life, since we cannot restore it once gone.

Q16

I suspect most people who appoint welfare attorneys do so in anticipation of extreme, life or death, scenarios. Therefore, it would seem right that the attorney's view be final. You only mention refusing treatment, what about insisting on treatment? On the whole, I don't feel that the view of a detached professional should override that of a spouse/partner/child/parent. How does a spouse etc live with the feeling that they couldn't protect their loved one when it mattered most? Professionals will move on.

Q17

I'm not a big fan of advance directives. To my mind they are another symptom of the desire for absolute control over everything which permeates life today. If they are not going to be taken into account, then obviously they are not worth preparing. I would rather trust close family members to act in my best interests.

I also base my view that people often do not know how they might react in a given situation on my own experience. In my first pregnancy I read about cases where the baby dies before birth, and to my absolute horror I found that mothers would have to go through labour and deliver the baby in the normal way. This seemed so barbaric to me that I begged my husband to pay for a caesarean if it happened to me. It didn't happen in that pregnancy but in the next, and of course when it did I realised that the only thing that remained for me to do for the baby was to give him a proper birth - it would be my only memory of him. So I believe similar unforeseen views can emerge in other situations.

Q18

No views or relevant experience.

Q19

Like most things, this is not a black and white issue. In my experience whatever you say will not detract the person with dementia from their own 'truth'. Whenever she was in the bath, my mother used to insist that she had to get out at once because the Queen was waiting for her outside. It did not matter whether I contradicted her or played along with the story, I knew nothing. The real problem was that she hated the water. The most important bit of advice I was ever given as a carer was that "You cannot win". It's probably worth remembering how we approach truth with children. We keep it simple, avoid unnecessary harrowing detail and try to gauge how much they can cope with.

There seems no point in distressing a person with dementia unless it is absolutely essential, if a close relative has just died for example. Remember that whatever you say may well be forgotten so don't beat yourself up if you think you got it wrong. Remember best interests too. Disguising medicine in food or drink is not always about a person refusing it because they don't want to get well, probably rarely. It is more likely to be about an unfamiliar or forgotten action, or something unrecognisable (a tablet perhaps) that they don't know what to do with.

Q20

Professionals often err too much on the side of caution - I suppose they are watching their own backs. Wandering seems to be a big risk with wives - perhaps I'd be the same with my husband, though I hope not. If the risk is only to the person with dementia then I would hope to go on as usual as far as possible, but with things like driving, when others can be unknowingly put at risk, then it may be necessary to intervene.

Q21

In your examples of restraint, the only one I've used is the 'bundling' into the car. But I don't see this as resisting getting in, it's not knowing how to and not understanding the instructions. It looks to me that people with dementia can often do things as an instinctive action, but once they are required to think about it they are lost. I see this every day with such things as sitting down or getting out of the chair.

If the law is too detailed and prescriptive then it probably hinders carers. Don't forget they often have to act very quickly to avoid injury and don't have time to carry out a risk assessment.

I think it also important not to have blanket ethical policies - each case should be judged on its individual circumstances and the views of the person with dementia and their carer/next of kin. I've heard very recently of a lady being allowed to fall out of bed again and again because bed rails were felt to be an invasion of her freedom - freedom to fall presumably. Family members pleaded for rails but to no effect.

Q22

Again, it's like child-rearing. You can only really learn on the job, and no-one gets it right every time. For professional carers there can be some academic education, but the best learning will be done as shadowing experienced carers. Those of us caring at home probably wouldn't relish intrusion of an educator, but a help-line for enquiries about specific issues as they arise would be welcome. Alzheimer Scotland have a very good one which I have used.

Q23

I sit on the local telecare working group as the token carer. The main problem with encouraging wider usage seems to be with the time it takes for assessments, referrals and so on. People go into residential care, or even die, while they are waiting for the bureaucracy to swing into action. In my view, the majority of the technologies are not suitable for people with dementia since they involve new behaviours being learned. When she was still living alone, my mother could not grasp the purpose of the care-call pendant. She always put it on when she was going to the day centre! Also, many of the behaviours exhibited by those with dementia are only short phases. By the time a technological solution has been found, the behaviour has changed and a different problem arisen. One of the pill dosage devices proved impossible for even the occupational therapists in the group to operate!

There is also the disturbing feeling, denied of course, that these technologies are mainly being introduced as a cheaper alternative to human care. For instance, one monitor was designed so that a partner could leave their loved one alone in the house while they spend a couple of hours in the garden. If hubby got out of his chair the wife would be alerted by a bleeper she carried. I would not find it possible to relax if I could be beeped at any moment. But a visitor to sit with hubby for a couple of hours could talk to him,

make him a cup of tea, reassure him if he wonder where his wife was, and so on. Which do you think he would prefer?

CCTV would probably be expensive for care homes to install, and care homes do not come within the current initiative locally. CCTV and tagging clearly raise questions of privacy but they are the only technologies that actually could achieve what they set out to do. Tagging, of course, has criminal connections too with which some older people might not wish to be associated. But these are nettles which need to be grasped. Do we spend lots of money on things which are only partially effective, or go with the things which should work best.

At home we have a simple baby alarm connecting my mother's bedroom and our own. It's inexpensive and seems to do the trick.

Q24

The same duty as to any citizen in need, be they child, young adult or elderly. We are a society not just individuals. Though this country's laws are based on Christian principles, all the major world religions practice community values and have codes of conduct based on phrases similar to the Christian "love thy neighbour as thyself". Buddhism - Hurt not others with that which pains yourself: Islam - No one of you is a believer until he desires for his brother that which he desires for himself: Judaism - What is hateful to you, do not do to your fellow man: Hinduism - do naught to others what which if done to thee would cause pain. And so on.

It should also be remembered that most of the present generation of people with dementia lived through a world war and have contributed to the national insurance system all their working lives, which promised them care from cradle to grave.

Q25

I'm finding that support becomes more difficult to obtain as the dementia progresses. Some support groups seem to withdraw when the person with dementia no longer benefits so obviously from the support. Because she can't really engage in conversation now, it's harder to get people to keep her company. Bathing has become too difficult for the home carers, who only allocate 45 minutes. A good bath can take 2 hours from start to finish. I haven't really had experiences of conflicts needing to be resolved.

I do find little attention paid to my need for time with my husband just as a couple, or the needs of my teenage son. Having said that though, I do feel that it is best just to take life as it comes, this is how our family is at the moment. Lest you should feel I paint a rosy picture of caring for my mother - I have raised four children to adulthood without resorting to the F-word, but my mother has driven me to it!

Q26

I have a good relationship with our social worker. I think she feels I should let my mother go into residential care now, but doesn't push it. They must feel like piggy-in-the-middle trying to resolve some of these dilemmas.

Q27

My own might be a case in point! (see 25 above)

Q28

It should be the other way around - how much should families share with professionals? I do find that carers in homes I've used for respite don't tell me much. Everything is always "fine" and my mother is "no trouble". But I don't think these are confidentiality issues, rather a combination of what they think I want to hear, and not wanting to admit that they, as 'experts' might find things difficult.

Q29 to Q31

I've had no involvement in research issues so can't really comment. I just hope the defeatist and negative attitudes that I've encountered in some quarters do not prevail and thwart research funding.

Q32

I suppose it comes under confidentiality or invasion of privacy, but I do believe dementia patients, particularly in general hospitals, need to be discretely identified to all staff. I do have personal experience of this when my mother was at an earlier stage in her illness, and would always provide helpful (though totally inaccurate) answers to questions asked by staff. Because I was nosey and read her notes I was able to point out these inaccuracies to staff, otherwise there could have been significant implications for things like her discharge. I think this can be as important as identifying, for instance, diabetics, which I understand is done. No stigma of course to diabetes, nor should there be to dementia, and surely this view should start with the medical profession?