

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.

1

I would imagine that the impression sufferers of dementia experience is one of bewilderment; not quite understanding the things around them, but possibly also without the mental capacity to enquire. The hardest part appears to be that point at which the person realises that things have gone into sharp decline, but before losing the intellectual capacity for introspection and anxiety.

The impact on family/carer is that of intense alarm, panic even, at seeing an adored person succumbing inexorably to such a demeaning and undignified shadow of their former self, and the helpless inability to halt their decline. There is a crisis of conscience for the carer in dealing sensitively with such an awful disease whilst, at the same time, dealing with the frustration of frequent questions that are repeated endlessly, but the answer is never retained for any length of time at all. The question is never forgotten: the answer is never remembered!

No member of society should be cast onto the scrap-heap of life simply because they are no longer wanted, no longer spend money and no longer vote! It is absolutely incumbent upon society (at a personal and 'state' level) to ensure that all people are treated sensitively and with dignity through whatever disability befalls them. People should never be allowed to become 'inconvenient'.

Support for carers at a personal can have a great impact. Friends' support, understanding and encouragement is of great value. GPs, on the other hand are variable – mine was rubbish!

2

The only ethical problem I faced was that of a male (son) carer dealing with intimate aspects of a female's (mother) personal needs. We achieved this most of the time, even if it descended into Whitehall farce from time to time. At the very end, all dignity was lost in the need to deal with events as they occurred. I think that, by this time, my dear mother had no concern for dignity, and was relieved to be back again in the comfort of her own bed and in the peace of familiar surroundings.

3/4

I have no knowledge/experience of the requirements of different ethnic groups and therefore unable to form an opinion.

5

Not sure I understand the question really. Any possibility of a long-term scientific means of halting or suppressing the disease should be vigorously

pursued. In the meantime, a clearer understanding of the handling of and treatment for existing sufferers/carers is also of high importance. The longer term prospect clearly has the much greater significance for society in general, but that does not, of itself, mean we can neglect our social responsibility towards a very real existing problem.

6

I suppose that the value of early diagnosis is in direct proportion to the efficacy of remedial or suppressant medication/therapy available. If a sufferer's decline can be significantly arrested as a result of early diagnosis (and subject to his/her agreement) then early diagnosis would seem to be beneficial. Failing this, there seems no point in providing a diagnosis that will only add to the sufferer's anxiety without offering any potentially positive prospects.

7

I think society perceives dementia as a disease that renders sufferers beyond the range of social norms and beyond communication. The disease effectively isolates the sufferer from mainstream society. There is the feeling that the sufferer cannot respond to sympathetic emotional support and is therefore 'alone' in some hideous personal nightmare. I think society perceives that, because of this, there is little that can be done other than attending to the practical necessities of everyday living. The close family continually struggle with the desire to provide moral support and succour, but find that they are ineffective and therefore constantly frustrated.

8

If there is any saving grace to this awful disease I think it is that sufferers seem not to be aware that they have it, and are therefore blissfully ignorant of any difficulty or stigma that attaches. Family members may feel some embarrassment and possible stigma as a consequence of the decline of a once proud person; their failure to recognise familiar faces, join conversations and constant repetition of the same question. This may result from the feeling that it is somehow necessary to apologise on behalf of the person (whilst the 'inconvenienced' person is in turn embarrassed to receive such an apology. What it is to be English!)

9

I am sure people with dementia should be included in the every-day life of the community wherever possible, although I have found that it is not always easy to motivate them to take part. Friends were always very understanding and supportive – maybe the wider world is less so.

10

My view has always been to care for the sufferer in such a way that causes them the least discomfort, anxiety and negativity possible. I have tried to maintain the respect which is rightly theirs and, of course, the unconditional love of bygone times. I presume this forms part of what is described as

'person-centered' care. The difficulty arises when the sufferer is asked to do something against their current instinct. Maintenance of personal care can be a difficulty: I think things like this are a discretionary thing. Whilst standards might be somewhat more relaxed than in former times, judgement suggests that a reasonable level of personal care should be maintained. Other behavioural traits which may, say, put the sufferer (and others) at risk – leaving gas-taps open etc. – must be fully regulated – but with sensitivity. I suppose it's a matter of judgement by the carer: to what degree is it possible to let things 'slide' without causing unacceptable safety, health and public outrage.

11

Not sure exactly what 'identity' is. In my limited experience, I felt that the essential characteristics that had always defined the person (humour, prejudices, affection etc) were still present after the onset of dementia. The disease seems to take away the person's awareness and cognisance of events happening around them, but not really change the core of their essential personality, except that it might perhaps have exaggerated some earlier traits.

12

I'm not sure that I have had to deal with changes in mood, hence this has not been a factor in straining family ties.

13

I suppose a person's past wishes should be respected insofar as they do not reflect in an unacceptably negative way on their current circumstances; in particular, the provision of their care, their safety and that of others. Inevitably, this pivots about the careful and objective judgement of the responsible person, but such decisions should not be taken lightly. I have a connection with an elderly person who lives, unnecessarily, in squalor. She could easily afford a vast improvement, and her health/safety is not at particular risk, but this is the way she prefers to live and any intervention would be wholly counter-productive.

14

The person referred to above (Q13) is in the position of living alone with mental difficulty (not dementia), but with a little help she just avoids coming within local authority supervision. Without a small amount of voluntary support she would lose her independence – such a loss would, for her, be catastrophic (whilst also presenting the local authority with immense difficulty). The Establishment is entirely indifferent to people in this position; without co-operation from the government, local authority and the high street banks, people such as this are cast adrift and of no consequence. The approach taken by such organisations should be to live up to some sort of moral responsibility and remove arbitrary obstructions which make the lives of the frail and vulnerable so difficult. (Raw point!)

15

The appropriate care of any sufferer can only result from careful consideration of the persons circumstances by all concerned (medics/carer/family ... possibly others) on a case-by-case basis. Probably quite difficult to achieve in practice; maybe some sort of qualified arbitrator could help to maintain a degree of objectivity.

16

It would seem to be highly dangerous to cede the final authority of any serious decision to either the welfare attorney or the health professional. It could be argued that either party might reach a conclusion that would suit their own convenience rather than that of the person with incapacity. Where there is a significant difference of opinion, I would have thought a qualified, but independent arbitrator, able to weigh up both views, would be the best forward – especially if they were also able to hear from other people who have known the incapacitated person over a long period of time. The seriousness of the dispute might be hard to quantify: lesser cases might be better left to the welfare attorney's discretion with the health professional taking them to arbitration only if he/she held particularly strong opinions on the matter. Maybe that should be the operating principle for all disputes – with the welfare attorney assuming primacy in any decision-taking, and the health professional able to take the case forward to arbitration wherever he/she held a strong contra opinion.

17

I think advance directives should be actively encouraged, but they should try to give the person's views in a wide range of possible circumstances. The all important quality in question is the quality of life, and maybe it would be helpful if the directive gave some advance insight to the person's view on the matter. Some dementia sufferer's appear to take no interest in anything, respond to no stimuli, and any advance directive to withhold medication might be recognised with a clear conscience. In the case cited (Mrs. A.), she would appear to be reasonably contented and not under any stress from confusion or depression and therefore able to take some simple pleasures in her life. Had she been able to address such possibilities in her directive, the subsequent execution of her wishes would have been that much clearer. I have no idea how advance directives are made, but if they are to be legally binding, maybe they should be expressly *required* to address a wide of possibilities. Perhaps they should be legally 'ratified' at the time of registration, rather in the manner of a will, before they have any legal status. It would only ease the problem slightly of course, since it still leaves others to finally determine what constitutes person's quality of life.

18

Unfortunately I am not sufficiently au fait with current mental health legislation to be able to form any opinion other than that I have no faith whatsoever in any

government to provide any effective, enforceable and sympathetic care for the frail and vulnerable in our society.

19

I like to think of myself as an honest person, but I have had no compunction at all in telling 'lies' to a dementia sufferer where it would otherwise have caused distress or anxiety. When my dear mother, who had only a failing control of her bowels, fouled the carpet on the way to the toilet and asked what the stain on the carpet was (after I had cleaned it up) on her return, I told her that somebody had probably spilt the coffee or something. She seemed satisfied with this, but would have been mortified to have learned the truth. To have told her the truth would, in my opinion, have been quite unforgivably cruel.

20

As with fully-able people, people with dementia should be protected from the over-zealous 'risk assessment' brigade. Provided the risk is not extreme, and does not implicate others (eg. road traffic), the sufferer should not be protected from all imaginable risks at the expense of enjoying their normal behaviour and surroundings. The example of bed rails is a good one, but one which might be enforced only if the sufferer had a history or inclination to fall from bed. It's a question of balanced judgement in place of rigid procedures.

21

I suppose that, in extremis, any form of restraint is permissible, but only in strict proportion to the task at hand. Sedating someone, or leaving them unable to move, merely for the convenience of the care home staff, seems thoroughly unacceptable. On the other hand, if a patient is disturbing and/or threatening other patients through uncontrolled and aggressive behaviour, physical restraint would appear to be an acceptable way of restoring order for the greater good of the larger number. I have no idea how this works in practice, but at the expense of ever more bureaucracy, a log of each incidence of restraint and sedation might help to maintain an overall picture of the care home's general ethics. I would imagine that, in the immediacy of each situation, the hands-on staff have to make a balanced judgement, but each incident above a certain level should be 'signed-off' by the superintending medical officer, even retrospectively. Such a procedure would ensure that the person with overall responsibility could not be shielded from the day-to-day running of the home, and therefore fully responsible for its actions. The law is, as ever, desperately unhelpful in its prescriptive attempt to foresee every situation, whilst devaluing reliance on an informed, compassionate and intelligent response to the circumstances. Mistakes will be made; the really important thing is to avoid repeating the mistake.

22

From personal experience, there is very little support for dealing with the day-to-day care of a dementia sufferer. I doubt that some loose, flabby and time-consuming 'course' would be of much use, although counselling, particularly on

a specific point could be very supportive. Carers are often referred to their GP which (in my case) was wholly ineffective ("Just deal with it!"), although some dedicated branch of mental health care support could be very constructive. I think that an informal group of carers in similar situations could also be fairly therapeutic.

23

Not sure what ethical questions are raised by 'passive' technology (closing taps etc.); not sure either what is involved with remote health monitoring. In principle, it does not appear to be overly intrusive, provided that it does not involve active participation (logging-on to a network etc). Tagging does not appear to be overly intrusive either, except that if wandering is considered to be a significant risk, the patient should perhaps be under closer immediate care. I would imagine that the uptake of new technologies has to weigh the cost in money/time/complexity against the perceived advantage on offer; there may also be an element of denial of the perceived risk. Also, nothing is adopted in today's image culture until it is perceived to be fashionable. Video monitoring of care homes may well provide relatives with a peace of mind, but I'm sure it would be strenuously resisted by care home staff (how would **you** like a camera watching your every move at work?).

24

I think it is hugely important that society as a whole should recognise the need to support and assist people who are involuntarily frail and vulnerable, whether through Dementia or any other cause. These people have often led constructive and contributory lives up until the onset of old age/disease, but since they then neither vote nor spend significant amounts of money, they become an inconvenience that can easily be shoved aside without troubling the conscience too much. This is not only inhumane, it is also a very short-term policy, not allowing for the care that you and I might also need one day!

The carer of last resort must inevitably be the state, whether by providing the actual humane hands-on care, or by funding, either in part or in whole, the personal care requirements deemed necessary for the individual. 'Care' is the non-negotiable aspect; the state must not be allowed to get off the hook by simply signing a cheque and forgetting it, or by hiding behind an endless stream of meaningless glossy headlines and 'initiatives'. The state/local authority must know what care is required on a person-by-person basis; that it is both enacted and effective and that the department is fully accountable. Personal experience as a family carer of both central (DWP) and local government showed that both were unaccountable, unresponsive and highly obstructive in dealing with my legitimate requests. It should not be necessary to have to resort to MPs or Counsellors to resolve these requests. Also, the institutions that form the foundation of a functioning society (banks, utilities etc) should be statutorily obliged to provide an accountable responsibility to facilitate the frail and vulnerable with their services. (Recent experience with a high street bank showed that this is not currently the case.) My direct experience of dealing

with large institutions on behalf of frail and vulnerable people is that they, the institutions, simply do not care.

Who pays for it? Simple: we all do - the only question is how? It will be funded either from our own assets, or by the state, but 'we' all pay for it in the end. What is required, of course, is a grown up debate about what we want to receive from, and what we want to pay towards, taxation. This is never going to happen though; we don't 'do' grown up debates of this nature; the political machine can't countenance the loss of votes from unpopular policies and the electorate assumes ever greater demands on the state at no increase in taxation. None of this is helped by the very low standing of our politicians, and their robust reputation for wasting money. All of this means that we will muddle on well into the future with endless squabbles about funding, whilst the frail and vulnerable suffer on the sidelines. So – in short, the state owes the people joined up government, in this as in everything else. As if!

25/26

Conflicts might, in the first place, be best resolved through counselling. If the government feigns support for carers, then this might be the sort of thing that could bring benefit. My own experience was to attend a Mental Health Clinic with my mother. The patients and carers went to separate groups and, although the tenor of the group was rather 'stiff' and formal, it made me realise the difficulties experienced by others, and possibly gave me a calmer attitude towards dealing with my own situation. If counselling fails, I would imagine that state intervention would be required, but only in extreme cases. In lesser cases, the intervention might be more damaging than the conflict.

The business of ethics is hard to quantify: part of the professional carer's training should be to have a sympathetic understanding across a broad range of religious, cultural and ethnic backgrounds, and deal with individual cases in the light of that understanding. My own experience has been to listen to, and thereby absorb, a person's ethical principles over a period of time, enabling me to act and react within the known boundaries of their beliefs and often suppressing my own contra-beliefs.

27

I would imagine that state intervention might be appropriate if the carer was in imminent danger of serious mental breakdown him/herself, or if the patient had become far too difficult to handle. There is also the difficulty of the physical strength required to handle seriously impaired patients, which might be beyond the capacity of some carers.

28

In terms of patient/customer confidentiality, my own experience was that a letter to all concerned ceding authority to discuss my mother's private affairs with me was highly effective. There was never any difficulty discussing her medical circumstances with her GP – who gave her excellent care. I always

wanted (and expected) the full facts and hope that nothing was withheld, whether I agreed with it or not. The only reasons for withholding information might be where it could be more than the carer could cope with, or where it might be a deeply depressing forensic analysis of the patient's decline, irrelevant to the provision of immediate care. Again, I would imagine that discretion in these matters might result from the professional carer's training.

29

Whilst the humane care of today's sufferers is obviously of huge importance, the far greater goal must be to research ways and means of arresting the development of the disease in tomorrow's potential sufferers. Any positive research would not only bring great social benefit, but it would, in the long term, also bring huge economic benefit for the country as a whole. Funding is always a difficult question, but I would imagine that it should be weighed in proportion to other great research causes (cancer, heart disease, stroke etc.); the long-term projections of the likely cost savings in the care of future generations, and, of course, the likelihood of discovering a significant scientific breakthrough.

This is clearly a difficult social/scientific/economic argument, but one that should not, in my opinion, be coloured in any way by a perception that dementia research is not 'glamorous'. People, like me, in their sixties, are increasingly aware of those of their parents' generation who are affected by the onset of dementia, and the questions that raises. As life expectancy increases, so does the probability of dementia and the associated social and monetary costs – surely we should give high priority to anything that might relieve. Although the whole question is a very sensitive subject, I feel that it should be directed in a very hard-nosed and pragmatic manner.

30

I suppose the difficult word is '*research*' – what exactly is meant? If research is probing a patient by way of question-and-answer to understand their mindset, I cannot see why there should be any objection if it is preceded by a simple "*Do you mind if I ask you a few questions?*", and is halted if it induces a significant amount of distress. Something in the form of a test might be more stressful for the patient, and it would seem unfair to subject them to prolonged or serious stress. I would imagine that either form of enquiry should first gain the consent of the patient's representative, but should possibly be seen as a routine enquiry into the patient's welfare. Medicinal research would be a lot more difficult. I would imagine that this should be weighed against knowledge of the patient's former views; views of the patient's representative and the likelihood of damaging side effects. In the case of the latter, it would seem inhumane to expose the patient to unnecessary risk unless there was a significant chance that they could realise some long-term benefit, or, for some reason, it was the only way to advance some very promising research. Even then, it would be a grave matter of conscience.

31

I don't know what procedures are contemplated in the name of research. I could well imagine that some fairly 'adventurous' procedures might offer the prospect of scientific breakthrough, but at the cost of seriously intruding upon the patient's person, liberty and human rights. The only way I could imagine of circumventing this would be for a person with a fully explained understanding of the types of research contemplated, to make a 'living statement' of the lengths to which they would be prepared to go (in principle) in support of such research, were they to fall victim to dementia in later life.