

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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Dementia: ethical issues

Q1

- i) QoL – ensuring that a life lived with dementia is worth living and acknowledging that this is not only possible but also our responsibility. Our society values cognitive ability so highly that any threat to this ability is viewed as very negative and as negating the worth of the person whose ability is failing. People with dementia have this perception themselves. In my work I encounter people who tell me they are ‘Stupid’ all the time. They say they haven’t always been stupid but have become stupid. Stupid in this sense is highly correlated to ‘useless’ and ‘worthless’. This is a damaging event as it leads, in my view, directly to autonomy and decision making being taken from people who have dementia and to their ceding control of their lives because they are ‘stupid’. Most people, particularly professional carers think that life lived with dementia is not worth living, it is termed a living death, families describe being bereaved whilst the person is still alive. I feel very strongly that this is a betrayal of people who have dementia and one which professional carers too often perpetrate. How can we hope to improve QoL for people with dementia if we believe they would be better off dead?

- ii) The process of diagnosis disclosure and support offered there after has a huge impact on the lives of the people I come into contact with. Too many people still don’t get given their diagnosis, particularly if it’s dementia not caused by Alzheimer’s, people don’t know that Alzheimer’s causes dementia, questions are unanswered. Ensuring adequate and appropriate support following diagnosis disclosure – I believe it is morally wrong to disclose diagnosis without appropriate support. We need guidelines so that the process of disclosure and support there after is the same no matter where in the country you live.

- iii) How carers, particularly family carers respond to changes in behaviour has a huge effect on individuals living with dementia. Perceived loss of personality and the collusion between those without dementia that behaviour changes are organic and not, as is often the case, reasonable behavioural responses to new and challenging situations that the individual with dementia finds themselves in.

Q2

- i) I have concerns particularly around end of life and treatment/well being decisions. I don't believe the changes brought in by the Mental Capacity Act will provide the easy solutions some seem to be seeking. Given the way our thoughts and desires change as we age and face challenges to our accustomed and planned lifestyles handing responsibility to others because we may come to not understand the choices we may face or articulate a response is not a panacea. However this process will evolve hopefully with use.
- ii) Diagnosis disclosure remains an area that raises ethical issues, whilst we are much more aware that we should routinely be disclosing diagnosis many, many people remain uncomfortable with it and skills in managing this sensitive process are lacking. Ethical considerations also exist given that once diagnosis is disclosed support in coming to terms with or even accessing further information is not widely available. It is also very difficult for nurses when family members refuse not only to disclose diagnosis but insist that you do not. My professional code tells me that the information belongs to the client but often someone else has told family but not the person and the family then insist the person not be given the information – there is no support for me to give this information from within my management structure and on occasion I fear giving the person the information because whatever support I can provide alone is unlikely to be enough to help them to obtain the advantages of having diagnosis disclosed.
- iii) Advances in technology worry me, when we believe that piping relatives voices into someone's home to help them to settle at 3a.m. or install cameras or sensors to check what they get up to when alone is a realistic alternative to human care we are, I believe on a worrying route. These technological developments are welcomed by those anticipating an avalanche of caring responsibilities and who can't see a human way of dealing with it. Obviously some technological advances are useful but strict guidelines for their use and agreement on ethics of their use is necessary.
- iv) Personally the biggest concern I harbour with regard to ethical treatment of persons with dementia relates to what happens to people in 24hr care. We have become so good at enabling quantity of life but show little interest in enabling that life to have quality. Yet the research shows that this is possible. We are currently a nation obsessed with infection control and physical care, people looking for a care home for a relative are advised to seek a home that doesn't smell of urine – this is considered a measure of 'a good home'. Those caring for people with dementia are amongst the best physical care specialists in the country, but this isn't enough – I believe we are focussing on incorrect outcomes. People with dementia line the walls of 24hr environments, with no one to look at, no one to talk to and

nothing to do. Those who actively seek activity or set out to find some stimulation often end up labelled as challenging and become subject to medical treatments designed to manage the mental health needs of people with quite different diagnoses. The saddest thing is that in 24hr settings where activity and relationship aren't valued and are secondary to physical care needs everyone is missing out. Physical chores are demanding and tiring and not a lot of fun. Being involved in relationships and undertaking interesting activity is great fun and very interesting.

Q3 & 4

No comment. I work in an area almost exclusively white British – no non-white clients for the 3 years I have worked in the area so I can't comment!

Q5

I have more experience of the psychosocial developments and research on communication abilities, insight and supporting personhood and believe the research into these areas is compelling evidence for changes in practice. Whilst there are some stunning examples of what can be achieved in promoting positive life quality for people with advanced dementia these examples aren't infiltrating practice on anything like the scale they should be but remain pockets of excellence to be admired whilst our ability to replicate seems non-existent.

Q6

This is an interesting question, what I tend to do is ask what would we do if the diagnosis was cancer? The answer is; diagnose and tell as soon as possible (of course with cancer the prospect of treatment is more realistic so we feel more comfortable about being able to inject hope into the procedure). With regard to dementia I think this is the only reasonable conclusion we can come to. Make the diagnosis early and communicate it once the diagnosis is definite. Our concerns about disclosure stem from areas of our own fear of disclosing, our fear of prompting suicidal ideation or desire to let the person have as normal a life as possible for as long as possible. However I feel it is only when we start to treat diagnosis and disclosure as we do other disease or illness diagnosis that we can truly begin the process of 'normalising' dementia, by this I mean reduce the stigma and work as a society to improve the potential qol for people with dementia. There will always be variables around the process of disclosure and individuals communication skills; but I believe we should establish guidelines for those in a position to disclose to follow.

Q7

Society as a whole seems to be becoming used to the term Alzheimer's and to have an understanding of this, although largely negative and something to be avoided. Most people have a perception that Alzheimer's is a 'living

death' that destroys personality. I still regularly come across people with Alzheimer's who don't know what dementia is (or that they have it) and people who know they have dementia but don't realise what that entails. A campaign similar to that which brought Alzheimer's to the populace and continued use of high profile figures together with more positive portrayals in the media are required so that the doom and gloom that is associated with Alzheimer's and dementia can be balanced against the positive experiences of many living day to day with dementia.

Q8

Huge – and people who have dementia experience it daily, it stops them going out, pursuing hobbies and interests, separates them from their families and community and leaves them feeling a burden and useless. Cognitive ability is so highly correlated to usefulness and self esteem in our society that where there is an impairment in cognition stigma isn't far behind. Indeed people with dementia stigmatise themselves to some extent. I run a memory group and the thing people attending the group most often say in relation to themselves is 'I'm stupid'. So common is this that at the beginning of each session we display a poster that says – 'I might have a poor memory, but I'm not stupid'. This is important because if people with dementia believe they are stupid they are in no position to defend themselves against such allegations by others.

On a funnier note a lady I know with dementia was recently highly delighted when her daughter left out odd socks for her to wear, she was gleeful as she could now defend herself against the accusations her daughter made about her 'getting things wrong' – her daughter is capable of mistakes too!

Q9

Yes. Stop treating 'them' as people with dementia and start including 'them' as people, for this is what 'they' are

Q10

Person centred care has led to the cessation of many undesirable practices – bathing people together in rows of baths, sitting people on metal commodes in rows, restraining people in Buxton chairs, sitting people bare bummed on incontinence pads to list a few from memory. We have come a long way, but only so far as to emphasise how far we have yet to go. The principles of pcc are fuelling progress, in my opinion.

Q11

This, in my opinion is the most damaging belief most widely held about persons with dementia. It allows loved ones to abdicate from love and relationship and encourages the formation of new negative relationships. It is belief that allows carers to call the person with dementia 'little princess' or

'grumpy old bugger', it detracts from identity and is (In my opinion) the final insult to the person with dementia. It seems we accept that people can change when they have other illnesses (for example someone who lives in chronic pain) but can only view it in terms of pathology when it is dementia. We term someone 'aggressive' when they object to being helped with intimate personal care, families report the person has never been aggressive before but no one asks whether the person has needed help with intimate areas before!

Q12

Research tells us that some changes in behaviour – for example incontinence and aggression have such a powerful influence on relationships that they are closely related to the move to permanent care. My own experience is that such changes encourage relatives and family to distance themselves from the person as discussed above

Q13

An ethical mine field with the potential for being unable to do right for doing wrong! 2 items influence my opinion on this area – firstly reading an article by a journalist whose mother had always insisted she not have any active intervention should she become unable to care for herself who, having had a stroke begged her daughter to prolong her life at any cost. Secondly some research undertaken with speech therapists asking their opinions on life prolonging treatments that demonstrated differences in preferences related to age; older therapists wanting more intervention. It is very difficult to predict your own preferences for a time when you are unwell at a time when you are healthy – it is amazing how people come to terms with vastly different life styles. So I believe we should rely on reading a persons' present behaviour but this is not a simple or even sometimes possible option!

Q14

If it is 'only just' then the person should be able to contribute something to enable decisions to be taken in their interest, the key is often how not what we communicate and we need to remember that capacity is an issue by issue basis.

Q15

A diagnosis of dementia should be influential only in terms of what the research tells us about outcomes for certain treatments, for example Volicer's findings regarding certain treatment options. See - <http://www.alz.org/national/documents/endoflifelitreview.pdf> For example; survival rates following cardiac arrest, outcomes with PEG feeding, outcomes following admission to hospital.

Q16

I think many are worried about how technology is being and may be used in care of people with dementia. For example there seems to be increasing support for the use of GPS as a means of allowing people with dementia more freedom – so they can leave their environment if they wish to walk and there is less requirement for restriction as GPS solves the problem of the person getting lost. However having GPS provides reassurance for the person *looking* for the person with dementia, not for the person with dementia themselves who may quickly lose track of where they intended to go and why and may become very upset and anxious, this together with potential risks for safety with regard to traffic or other outside environmental risks means we need to think very, very carefully about employing GPS or similar tracking devices.

Similarly some of the smart house suggestions cause me concern – the idea of piping a voice into someone's home in the middle of the night to encourage them to go back to bed and orientate them to time is very Big Brother – were it me I would be looking for the source of the voice, particularly if the voice were of a family member. I believe these 'advances' too often appear appealing because they reduce the need for a human to provide support and offer a reduction of stress for a carer but in reality they are at best poor alternatives to human contact. It also worries me that the companies who market technology have the benefit of huge marketing budgets that means the positive aspects of the product can be propounded and weaknesses or potential ethical problems minimised.

I am not against technological advances to make life easier for people who have dementia but I think we need to be very cautious and thorough in our investigation of both positive and potentially negative outcomes.

Q17

I think we should take a very balanced approach and ensure that people are aware that such documents can be legally binding and decisions directed in a time of health to be applied in situations of ill-health, whilst offering a margin of hope to have your opinion considered in a time when it can not be offered with capacity, are not a cure all. Things change, how can any of us know what we will want in the future? We can only imagine what we might want, if we complete an advance directive, develop dementia and lose capacity we have to hope our opinions don't change and we become hostage to decisions taken at an earlier life stage.

Q18

I have yet to have some direct experience of the act in practice but definitely welcome it as a step to addressing difficult issues – once we have it we have something to kick against, capacity and decision making issues are now well and truly in the professional and public domain and can't be ignored.

Q19

Yes, there are circumstances when it is permissible to lie to people with dementia. When life and safety are at risk. Unfortunately lying to people with dementia is fairly routine in care situations with the aim of making others lives' easier. In my opinion much of the technology being suggested for use in care of people with dementia relies on lies – for example the activation of speakers urging a person to return to bed when they inadvertently mistake night for day and walk around in the night, often using a familiar voice. Such interventions may work, but then a ward manager I worked with used to tell women with dementia in search of their children to wait in a certain place as the bus was due any minute – and that worked too!

Q20

Too much, as a nurse my experience is that nurses are defensive (myself included!) Most would rather justify a restrictive action taken in best interest than try to justify a negative outcome that was based on enabling freedom. I feel the blame culture within the NHS is largely responsible and can't see that improving any time soon. Codes of practice, PCC and changes in the Mental Capacity Act will encourage discussion and hopefully enable change.

Q21

Yes, but only to protect a person or other persons from injury. The Mental Capacity Act and Mental Health Act give guidelines, probably not specific enough but again should generate debate that will move us forward.

Q22

Yes, education is needed in order that carers recognise and understand ethical aspects involved in decision making. Some practices in some care areas are so ingrained that carers don't even realise that their practice is open to question and that there are other potentially 'better' ways of working. Real life scenarios that are easily recognisable need to be used and questions posed, frequently ethically questionable practices (e.g restraints by use of low chairs that people can't get out of or using feeder cups) are not seen as 'wrong' so the problem needs to be addressed from philosophical and practical angles. In my experience nurses do worry a lot about situations once ethical questions are raised and generally use their own, personal frameworks for sorting through the issues. I worked on a ward where we were considering PEG feeding for 2 very young women with very advanced dementia (ages 60 and 62) and the level of discussion was intense (this was before the research evidence suggested that this wasn't a successful option in care of persons' with dementia). When I consulted the literature on the subject our discussions very much reflected the intricacies of the issue – what was most interesting was that the split in staff opinion for or against was directly in line with people's religious beliefs!

Q23

No comment

Q24

A duty of care is owed, as it is owed and offered to every citizen under the NHS. On a broader basis everyone who lives long enough will eventually get dementia and denying care, treatment or services is not in our interest. If services don't adapt and change people with dementia will become further marginalised and stigmatised, as by sheer volume of numbers they increasingly demand more resources. This is something health and social care staff have to seriously consider, often even as we gate keep services we are the ones stigmatising and denying people. Just the other day I heard a senior health spokesman on the BBC news referring to people with dementia as 'Those people', if we see and describe people with dementia as 'those people' what hope is there for equality of resource allocation? Older people are already seen as consuming far too much in the way of NHS resources with little dialogue about the logic behind the statistic and we need to be very careful how we present ourselves and the language we use in order not to alienate the public further.

Q25

Two things need to happen; firstly care services (primarily health and social) need to consider how they label people as carers – this happens automatically with absolutely no consideration to the labelled carers agreement. People are labelled carers on the basis of family relationship or sharing the same house. This is wrong and suggests we make assumptions about peoples abilities and willingness to care and creates conflict in many areas from the outset. Secondly we need to apply evidence base that shows communication with people with dementia is possible even into the late stages of the disease – this will enable us to better include the perspective of the person with dementia in areas of conflict.

Q26

I believe professionals hold a key role in advocating the interests of the person with dementia but too often feel that it is the carer we advocate for and support them in ending the caring relationship when they appear to have 'had enough'. There are no easy answers, the types of support that would help people carry on – care packages built around individuals rather than what's available and how much it costs would be good.

Q27

As my previous answer suggests in my experience I don't believe that professional carers do solely concentrate on the person with dementia. I believe we try to strike a balance taking everyone's needs into account but this often doesn't work no matter how hard we try.

Q28

I think family carers are frequently given information as an alternative to that information being given to the person with dementia and without the

person's knowledge or consent. This has to change over the coming years – what has to change is professionals approach as they are the sources of such information. We need to look at why we give information to others without consent, what we are hoping to avoid and gain.

Q29

Research should be aimed at finding cures and treatments and on improving quality of life for people who have dementia. Funding should be allocated on a par with other long term, chronic health problems and be reflective of the scale of people likely to be effected.

Q30

People who lack capacity must be involved in research; otherwise our ability to answer questions about their needs and circumstances are compromised. Lack of capacity to assent to being involved in research doesn't preclude the persons potential to be able to contribute meaningfully in a project. Obviously there needs to be a rigorous system or process for protecting the rights and needs of individuals with regard to how and what they are involved in.

Q31

I don't know enough to comment

Q32

What should we do when a relative who has been given the diagnosis insists we don't tell the person?