

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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What is dementia and how is it experienced?

Q1 In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most by people with dementia and those caring for them?

The greatest impact of dementia on the individual and their family, is how uninformed we all are about this condition actually is, and then not having sufficient time to make the necessary adjustments. It was only after my Mother was diagnosed with advanced dementia (Alzheimers) that the effects and risk were brought home to both of us. Only then preparations for her future could be made, in effect we had little time to pre plan, and had to make the appropriate adjustments as we went along. This also had a very limiting effect on how Mummies care team was put in place as it was a case of having to take what was available at the time with no time to think or work out what type of career Mummy would both like and need, it took over 12 months to sort these issues out with the emphasis on presence and not the care or quality of service provided. Society very much took a I don't want to know approach and it was a case of very much proving Mummies capabilities than any of the issues she faced.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

The first ethical issue that affected my Mother was the total lack of respect for Mummy as a person, the hole process was putting her in a position that she was expected to comply with or fail, at no time was Mummies underlying personality considered. Mummy was a shy woman and had always been treated as if she would and could immediately react and respond to questions, test and procedures that were completely new to her, and quiet frankly very scary to her and if she did not respond the rite way this was a failure.

The second ethical issue was an over riding assumption that people new what she wanted and new what was best for her, Mummies input was not really taken in to account, she was treated as if every thing people were doing for she must like weather she wanted this or not, if mummy didn't like what was happening to her it was her 'condition' never the simple fact that she still had her own wishes, ideas and opinion the simplest and best example of this is she would have to watch TV programs she didn't want to watch and expected to enjoy this. Right up to the simple fact that Mummy still and always wanted to live in her own home, which we

achieved and from our experience it has amassed all Mummies Doctors, Social Workers etc, etc on the significant improvement in both Mummies well being and quality of life, and quiet frankly extended her life by years and assured her happiness.

Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

Yes: I have worked with careers over a considerable period of time and see the situation from both the careers point of view and the clients (my mother) a period of trust and friendship had to be built up in the first instance (it has always baffled me about any body who has dementia are expected to be 100% compliant with people looking after them who, they don't know, and don't always know what and why things are being done for them

Having worked with in the main African careers, they have always been surprised how our culture leaves the family to do so little and take no responsibility

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Just because some body has dementia does not automatically make them a nice or a more tolerant person, I have seen this creating very difficult situations between careers and their clients and these issues are just not looked into

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

I don't know of anything now or in the forcible future that will make any difference. In my mothers case up until she passed away in December 2005 their was nothing medically available that could help her. Even if there is now I can not see how it will be able to reverse situations or for example make some body regain a memory that they have lost. People who have dementia also have other issues even if its simple aging. I genuine believe that good appropriate career is the best way forward

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

As soon as possible, the earlier this can be done the better people with dementia change because they are growing in to a new phase of their lives, which will be different until this is properly known or understood people will try to continue to act out their lives the way they think they should and people will treat them in the same old way, this is why it becomes so difficult, until people have an idea that a change is taking place they won't respond to it.

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Fear! Simple Fear because so little is known about it or understood, I have never seen a 'Positive' program covering this subject, yet my Mother was very happy with her life right up until the end, and was living a quality of life far better than a vary large part of our society. Her life was just different to what it had been, its recognising this which is important and looking at the good things that are developing, when was the last time you went out with some one who said how wonderful the Sun is on their face, the breeze they feel and marvelled at the sight of a little bird. If you Judge People by the latest film star well what do you really expect? And for that matter who is having the better experience! Does any body talk about a baby living in nappies as that's all that matters no its just the lack of understanding

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

Part of 7 above and the view that it's only down hill, being treated badly and being shunned by friends and family alike, the over emphasis on bad things and a general sense of hopelessness. Society knows we don't treat our old people that well and dementia is the classic badge of the old

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

Yes differently, Mummy was a member of London Zoo and Kew Gardens and she loved going their, and we have had very many happy experiences with other people and children just getting use to seeing an old lady in a wheel chair having fun, this helps every one and showed how that life is not bad what ever you think. Weather permitting Mummy would be taken out and never once did we find this a problem. People with Dementia are part of our diverse community and it can affect every one, being hidden away is so detrimental to the person, taking even more hope and enjoyment from them

Person-centred care and personal identity

Q10 Is the idea of *person-centred care* helpful, and if so, in what way?

Yes it is, I've covered quiet a lot of these aspects above but there is not a one fix for all, it needs both input from the patent and the people looking after them to find the best way of looking after them and creating a happy environment for the patent and the careers

Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?

Dementia's make people grow into anther phase of their life, it's more like evolving than changing. Its not really about looking at what people were but what they are becoming some good and bad things may be lost but something new is emerging the persons new identity

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

Tremendous confusion, worry, fear and the not knowing what is happening or why, an over tendency to resist the change and this can cause irretrievable damage, as we are simply not expecting this or conditioned to expect this. This is now a society wide problem

Making decisions

Q13 When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

I have no experience of living wills, so I can only go on what I knew my Mothers wishes were, which I did right up to the very end and was supported by my family, from my experience and observations of dementia care wards, I have not really seen many patients whom have not wanted to get better and carry on living, even in very difficult circumstances. I have also seen many people harming them self's to go into hospital for companionship and care. This indicates to me there is not an overwhelming urge to end life prematurely and more one of people looking for a better quality of life, whom are not sure how to achieve this

Q14 What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

The individual's interest should be paramount, and if they are not in a position exercise their full capacity, then their representative should act in their best interest, with a balancing test on weather the representative is actually doing this if need be a referral to law would be necessary

Q15 How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

These two items must be looked at separately the diagnoses of dementia will not provide sufficient evidence of the degree of dementia, clearly if a patient needs life-sustaining treatment with out the full knowledge of the level of dementia is having on the patient with out looking at tease separately their will be a tendency to magnify the life-sustaining treatment as not in the patents interest which could not be the case

Q16 What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

Health professionals don't have the full picture of the condition of the patents; their judgements are clouded by their experience and brief diagnoses. They don't usually have access to all the patents full medical notes and care notes, putting

them at a disadvantage against the experience of the welfare attorney whom is client based as opposed to patient ie an ongoing knowledge of the individual, not only when needing medical intervention very often by an unfamiliar medical professional

Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

Peoples should be encouraged to make advanced decisions; but these should then have a minimal roll in decision making, as simply the current Social clement has instilled the idea that being sick and old is bad, and many people have found out when they get their its not as bad as they have been lead to believe

Q18 What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

I don't know this

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

No: how ever painful this is it is not rite to impose your value on to somebody else

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

This is an area were risk aversion prevails as a result of the fear of league ramifications (negligence, Health and Safety) which restricts peoples freedom of action and very often limits their methods of communication which will then be come detrimental to the individual and limit their existence even further