

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.

The Field Lane Foundation

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?

Challenging behaviour and the loss of memory are the hardest things for the individual and family. Society people who have no inhibitions are also hard for society to accept and therefore stigmatised as inappropriate behaviour.

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

Consent for medical interventions, medication and treatment is the biggest problem for all concerned.

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?

All ethnic and cultural groups have their own feelings around dementia and dementia care. These need to be carefully addressed both in assessment and care.

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?

Medical research is the one factor that will make the difference for current and potential dementia sufferers.

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?

People should know as early as possible that they have developed or are developing dementia so their own appropriate plans can be made.

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?

Really society does not want to know about dementia. It is associated with age related decline and is a subject which British society has pushed under the carpet for too long. Dementia, in common with most illnesses tends to be perceived as something that affects others, it is associated with elderly decline and seen as an old people's disease. Research has indicated that people are more worried about getting dementia than they are cancer.

The numbers of people who are going to contract dementia is quite frightening enough to make people aware of the disease and need to be publicised and then publicised again. Any publicity campaign attempting to deal with widening awareness of dementia needs to break the linkage to age decline. Dementia and dementia care are things that are still hidden from view in a society that is notoriously insecure in discussing emotional health and well being. The fact that our materialistic society is particularly aged unfriendly (no longer in the economic cycle as producers of wealth and capital) also needs to be met head on.

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

Stigma plays a great part in the care. Carers are hesitant to put their loved one who is suffering from dementia out into the real world. There is a tendency for the dementia sufferers to be cocooned in a false world of coping until there is a crisis of care and when that coping is no longer sufficient.

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

Yes people should be included as long as there is integrity in the activities and the individual(s) are not compromised by the situation. However, concurrently there also needs to be a far greater acceptance of dementia by the wider community for such community access to be meaningful.

Person-centred care and personal identity

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

Person Centred Care is crucial to Dementia sufferers. This is because such care must focus on all aspects of the person. Thereby treating them and not their disease.

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

Dementia does not change the person's identity, they remain the same person. It is the change in their behaviour which provokes a change in our perception of the person that is the difference. In time the person with

dementia may not even now their family or friends, the difference is therefore in the eye of the beholder.

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?

Families are devastated by the changes to their loved ones. They are overwhelmed by the changing behaviour of the individual that they once knew and quite possibly relied on for support themselves. Now the roles can be reversed, the support is no longer there but the onus is on them to provide unconditional support to the one time supporter. The relationship power basis therefore shifts and can instigate varied psychological and emotional consequences.

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?

When judging the best interests of the individual, their past wishes and values should always be included in any care that they are involved in. Quite often current wishes and values are only temporary and largely based on the current environment that they are placed in. As a general rule it is perhaps best to give more emphasis to past than present.

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

A very careful approach should be taken when acting in the best interests of the individual. Extensive consultation with all those around the individual should be carefully taken before any decisions are made. All decisions affecting the person should be reached via the consensus of these consultations.

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

A diagnosis of dementia will always be a factor in such decisions. An advance directive given prior to illness is always appreciated and should be encouraged.

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?

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?

Everybody should have access to the making of advanced directives. It is a useful tool in the face of competency and mental capacity to make decisions around treatment (or non treatment).

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?

It has clarified the situation. It is a useful reference point in what were largely uncharted and muddied waters.

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?

It is never permissible to lie. It is sometimes inevitable to simplify an explanation but for the relationship to be valid then the truth must be paramount.

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?

Life is full of risks. Without risks we are unchallenged and not stimulated. It would be unreal to exclude risk from dementia sufferers, the risks involved can be mitigated by the quality of care and support around the person's life. The ability to take risks is life affirming and therefore should not be taken away from anyone.

Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

No restraint, ever.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

Guidance and training should be obtained from those who actually practice person centred and individualised care (and not those for whom it is a buzz word/phrase)

Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

These are all forms of restraint in another way. Dementia sufferers require human contact and help.

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

In terms of equal rights and access to benefit or relief when in need people with dementia are exactly the same as people without dementia. In terms of access to health services this should be paramount but in [practice is not always the case when GPs and consultants are sometimes unwilling to expend resources on dementia sufferers and others suffering from severe physical/mental syndromes.

The needs of carers

Q25 How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

A useful tool would be for a dementia mediation service to be set up, staffed by people with expert knowledge in the field who could clearly explain the situation and suggest the pros and cons of possible solutions.

Q27 In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a *couple* (or of a household), instead of concentrating solely on the interests and needs of the individual?

The interests of the individual should be placed above other considerations to prevent mistakes occurring. Family and carers are desperate to be successful in their care and coping. However, they are not always best placed to make dispassionate or more objective choices regarding appropriate levels of care for their loved one.

Q28 From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

Families can often be ill informed. There are no guidelines about confidentiality in regard to dementia and its care or treatment and these should be addressed and put into practice.

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

Medication and modern modules of care (there are no guidelines as to what works or is appropriate and what isn't). This needs to be publicised and clarified. Without meaningful consent dementia sufferers should not be subjected to trials of any kind.

Q30 What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

Please see Q 29

Q31 Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research which you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

As 29.

Other issues

Q32 Are there any other ethical issues relating to dementia that we should consider?

People with dementia would profit greatly from well informed advocacy services and the establishment of 'Dementia Champions' within residential dementia care and nursing environments.