

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.

Christian Council on Ageing; Faith in Elderly People
Leeds

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?

Marginalisation of those with dementia ('ageism plus') and isolation of family carers because of the 24/7 nature of the task. In society at large there is fear and lack of understanding; society demeans itself by marginalising people with dementia and their carers; inadequate funding for residential care and low pay for professional carers reflects ill.

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

We have noticed that it is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions (which will have great impact on their future well-being), thereby 'de-humanising' them

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?

Faith in Elderly People (Leeds) has found that there is a tendency within some Indian groups not to admit to the extent of dementia because it is seen as too shameful and a matter to be kept within the family. FIEP has produced and distributed leaflets about dementia in a number of different languages with no evident response. It has also experienced examples in African-Caribbean groups of religious leaders regarding dementia as a 'sin' rather than an illness and of the use of excessive restraint within the home. However, we understand that the Black Elders organisation in Leeds has had some success with a day forum focussing on dementia in their community.

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

The need not to appear to ride rough-shod over entrenched cultural and religious attitudes but rather understand them and gain the confidence and co-operation of community and religious leaders, for example in arranging forums. Some cultural groups appear to feel that there is less provision for them than for the 'middle-class, articulate, white British'; more equitable planning and provision would seem to be required. For example a day centre in North Leeds is looking at the possibility of having regular dedicated days for people of other ethnic groups with staff from those groups; this should make the provision more acceptable. Appropriate multi-religious chaplaincy in residential care would also be helpful.

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?

- a. Early diagnosis, giving time for people to come to terms with likely changes in their condition and to plan accordingly.
- b. The availability (provided NICE agrees!) of drugs such as Aricept which can set back or contain the progress of the disease for a few months and improve well-being accordingly.
- c. Electronic devices (tagging etc) which can provide greater freedom and protection, provided they are not used too restrictively.

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?

This will vary from person to person, and conceivably some would prefer not to know (though this may too easily be assumed). On the whole, early diagnosis and communication would seem preferable, provided that it is done with sensitivity and all possible sources of support investigated. Alzheimer's Society field workers seem particularly good at this.

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?

Dementia has 'come out of the closet' to an increasing degree, partly because of the closure of long-stay psychiatric hospitals giving greater public exposure and partly because the media are featuring dementia (advances in treatment, examples of bad practice) more sympathetically, as witness recent films and TV and radio programmes.

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

A large, but hopefully decreasing, part. Shame (that this should happen to me/someone in my family) and fear (it may happen to me – is it in my genes? – and I would rather not face that at present – is it somehow infectious?). The fact that some care homes seem to provide woefully inadequate care (though others are wonderful) intensifies the stigma, conjuring up a reminder of the old 'workhouse' days.

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

As much as possible. Keeping people in their own homes/local communities, with adequate support, is important. Day centres, lunch clubs and dementia cafes offer a great deal. Probably small groups are less intimidating than large ones. Church congregations and faith communities are very important for those for whom faith provides a 'golden thread' to their lives.

Person-centred care and personal identity

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

Tom Kitwood's pioneering contribution has been crucial and highly influential. It is vital to see the person rather than just the problem. We continue to be persons because others continue to treat us as persons. The person-centred approach has therefore now progressed to a 'relationship-centred' approach which recognises the importance of continuing relationships as well as the possibility of making new relationship for the person with dementia.

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

It certainly affects, but does not necessarily totally destroy, those aspects of personhood which enhance a person's sense of their identity (memory, relationships, creativity, choice, communication etc). However, if others assume that the 'real person has gone' and act accordingly, then it is very likely to be a self-fulfilling prophecy. Here again faith communities have an important part to play for their members, bringing a sense that they are still remembered by God and of significance in his eyes, as also in the eyes of the congregation.

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?

Considerable, especially if it is not understood why a person's mood or behaviour has changed (so-called 'challenging' behaviour, though sometimes the change is to become more amenable) which may well be out of sheer

frustration or fear/insecurity. This can so easily lead to a writing-off of a person's former values and wishes because it is assumed they are no longer really 'there'.

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?

A difficult one. A person's wishes and values should be identified by discussion and the involvement of family at an early stage. These can however change over time, whether or not a person has dementia, and so there may be need of some balancing. It is likely to be very difficult to track these in the later stages of dementia.

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

The suggested course of following expressed wishes unless demonstrably harmful would seem to be the best way to proceed.

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

It should make no difference in the earlier stages of dementia. The doctor may later be placed in a very difficult moral dilemma balancing objective value/subjective life quality. Welfare attorneys, provided they clearly understand their role/restrictions etc, have an important part to play.

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?

See above. Mediation and court procedures at such a late stage of life would seem to be needlessly lengthy and disputatious. Probably the welfare attorney's judgment should be followed except in extremis where the opinion of two health professionals (in consultation with the attorney) should prevail, thus relieving the attorney of sole responsibility for a decision they cannot bring themselves to make because of likely resultant guilt.

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?

The third position outlined in the consultation document would seem most acceptable. The case study of 'Mrs A' crystallises the matter well. The practice should be encouraged whilst recognising that many people are likely 'not to want to know'.

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?

There will need to be special vigilance to ensure that restraint or sedating drugs are used only when necessary to protect the person (or other persons). It is all too easy for hard-pressed and understaffed care homes to interpret this for their benefit rather than that of the resident.

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 quite often the case that a person with dementia assumes that their deceased parent/spouse etc is still alive. It will not be helpful to correct them abruptly in the cause of 'truth' – better to ask whether they are missing the person i.e. to communicate at the level of feelings rather than facts.

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?

In the case of one woman who lived happily for several years in a care home, agreement had been reached with the family that she should be encouraged to spend time in the garden and allowed to go out for walks (even though she sometimes got lost) because restrictions or restraint would have made her unacceptably miserable. Of course many other people with dementia are happier and can be 'more themselves' in a more secure environment. The forms of restraint described should be very much last resorts.

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?

It does seem to be true that care homes which are 'person-centred' and where there is adequate stimulation, with opportunities to be creative or to relax do not need to rely upon restraint except in the most difficult cases. Decisions should be made by care staff in consultation with the person concerned and their relatives on the basis of what will keep them safe

without over-restriction and recognizing that there are other patients/residents involved in a care facility.

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?

Definitely – both for professional and family carers. Once the consultation process is completed, a specific obligatory training module should be produced for staff training based upon the consultation paper and the findings. It would be an advantage if this could be related to the NVQ curriculum at its various levels. A specific resource should also be prepared for welfare attorneys. A leaflet for family members would be helpful and should be available through social/health workers/care home staff and the Alzheimer's Society.

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?

Smart homes are potentially very beneficial but here it is the financial and practical issues (e.g. will the gadgets bewilder rather than help already confused people?) that predominate over the ethical. Tracking devices (again relatively expensive) may be disabled or jettisoned by users who cannot understand or who resent them as unnecessarily intrusive on their personal freedom.

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

The duty of appropriate care and the willingness to enhance the quality of that care by paying or subsidising a realistic cost. Since family carers accept responsibility at great personal cost and save the country major expense, they deserve better information, advice, support, respite etc, not least groups where they can share experience and find mutual support.

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?

The conflicts would appear to be in two different directions. Families should be encouraged to continue to accept the responsibility of caring for their dependent family member as long as they are able but this should be

dependent upon the promise and delivery of adequate support. On the other hand, in the later stages of dementia when family carers are likely to be totally exhausted they need to come to an agreement that a care home might be the best solution for both the person with dementia and the primary carer – without a concomitant sense of guilt. Sharing the experience of others who have gone down the same path and found it worked well is important here. Maybe the experience of Alzheimer's Society field workers could be enlisted also.

Q26 What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

They obviously have a crucial part to play. See answer to 25 above. The good offices of an honest broker (e.g. via Alzheimer's Society) might be more acceptable to some.

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?

This is vital. Often the prospect of separation in advanced age, for example after 60 years of marriage, is hard to contemplate and might well hasten the demise of both parties as well as adversely affect their well-being.

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?

There do need to be clearer guidelines but the ethical dilemma is well set out on p32 of the consultation document. As indicated there, a welfare attorney probably does have a legal right to such information. If there is none but close family are involved it would seem to breach confidentiality in any major way if disclosure is of 'probabilities' re diagnosis and likely progression.

Research

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

My attendance at British Gerontological Society conferences indicates that not inconsiderable research tends to be devoted to either aspects of person-centred care or the value of technological aids. This should continue to receive grants but this consultation paper has also highlighted further work needing to be done

on ethical issues.

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?

Since further research is vital, unsurmountable objects should not be placed in the way of projects. Provided a project passes the criteria of the Clinical Trials Regulations, informed proxy consent should be sufficient, with the provisos of the Mental Capacity Act and the Adults with Incapacity (Scotland) Act which agree that there should be minimal risk or discomfort and have the potential to benefit the participant (or, I would add, those with a similar condition in the future).

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?

Not that I am aware of.

Other issues

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

The working party is to be congratulated on producing what appears to be a comprehensive and comprehensible document!