

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 progressive change in character and behaviour with the steadily increasing demand upon the carer to the point of almost total exclusion from all non dementia relationships. Those charged with the responsibility of delivering support should have dementia specific awareness training.

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

During the first 2 of 12 years of 'caring' the GP was reluctant to discuss the case with anyone other than the patient. As the husband and carer, this problem was resolved by going to another GP and starting again.

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?

The identification of the cause which would lead to more effective treatment and possibly prevention.

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?

Correctly worded with all tests explained as early as possible to allow all concerned to prepare for what will be challenging circumstances. Good news will always be welcome should an early diagnosis prove incorrect.

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?

Society is more understanding but there is also a fear about the implications of dementia.

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

The 'statutory providers' help to create stigma by delegating 'care' to their Older Peoples Services despite the significant number of people diagnosed whilst of working age and therefore requiring different services that are now always available. Statutory providers should be encouraged (and funded) to deliver condition specific services – not age related services.

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

This is the value of early diagnosis and help should be given to assist people to lead as full a life as possible. However this cannot be delivered by targets due to the progressive nature of the condition with individuals presenting so differently during the early stages.

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 helpful but professional carers (statutory providers and those in nursing and care homes) must fully brief themselves by talking to the lifetime carer and not base their assessments upon the evidence they can see.

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

Over time there is a profound change although the family carer will probably be able to see the real person.

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?

For the family these changes are very distressing but the family should also be able to see the 'real person' as well.

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?

To act in the best interests of the person with dementia requires an early diagnosis whilst still 'of sound mind' so that with carer/family crucial matters and a care pathway can be agreed without resorting to third party advisors introduced under 'the Act'.

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

Given a potential harmful/dangerous situation 'best interest' must be a course of action avoiding such positions in the first place particularly with a changing condition.

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

A doctor should consult with the carer prior to a decision on life-sustaining treatment along with the form of 'quality of life' that can be expected. In the absence of a carer/family, the new Act provides the guidance.

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?

This entire section ignores the vital role of the carer who in the majority of cases is the spouse and their views are paramount. The use of court appointed attorneys should be last resort in case without a carer. Greater weight however should be given to the view of health professionals in a case of significant disagreement. As a footnote, due to the NICE directive on drugs which is leading to a delay in case being accepted into secondary care, there is an increased risk that a form of 'denial' will be established with forward care and financial planning not taking place when the person is 'of sound mind'.

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?

Advance directives made when a person is considering 'in the unlikely circumstances' their future medical treatment, should not be encouraged beyond those people who seek to refuse medication as a matter of principle or religious belief.

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?

After 12 years as a carer for my wife I could only be comfortable with the truth. In certain circumstances it may be better to introduce a conversational diversion rather than deliver incorrect or potentially disturbing information.

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?

With dementia there is always going to be constraints and progressive reduction to freedom of action. The introduction of equipment/aids should be seen as a progressive improvement rather than a restriction allowing an improved quality of life – even for just a short period.

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?

Restraint has not been an issue in 12 years of caring.

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?

All staff working in care homes and Social Services departments dealing with people with dementia should have Dementia awareness training to NVQ level 2.

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?

Only the more passive form of technologies could be used and none requiring putting on, responding to or with remote voice activation – all for obvious reasons. Also any technology will be of limited time effectiveness as the condition progresses.

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

The state has a duty to fund research to find the cause of dementia and to finance the drugs to treat the condition. Such action would lead to a subsequent reduction in the level of funding per case as the period of high level nursing and care home care would be reduced. The state should also be aware that in diagnosed cases under age 65, the person with dementia, their carer/family will suffer a significant financial demand many years before the state is called upon for services which then should not means tested.

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?

Sadly there must come a time and the wishes of the carer must prevail as their health and ability to care become paramount.

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?

Professional staff must note the carers view and needs and not be motivated by their own budgetary or other policy dictates.

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?

If both parties are assessed as needing residential care, it would be better placing them together rather than to separate.

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?

Any individual professional care giver only plays a small part on the long journey that is dementia. If there is a spouse/partner carer, they should be fully informed of all information at all times from diagnosis onwards as it is only these people who are able to observe and report progress to the professionals. Information should never be denied to them as they will face very big decisions later.

Research

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

Cause, treatment and care.

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?

The question of involvement in research should be discussed at time of diagnosis when there is a reasonable assumption that people still retain mental capacity. Research considerations should never be considered at later stages by 'third party' welfare attorneys who have been appointed

on ethical grounds – their brief is the individuals care and not an altruistic ambition to further research programmes.