

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.

What is dementia and how is it experienced?

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

Balancing the need to keep an individual safe while maintaining their dignity and individuality. For example how to prevent someone from wandering outside when they may become lost, or be in danger on a busy road. Balancing the need for hygiene, food, medication when they are adamant that they do not want to be washed, fed or to take their pain medication, or to go for an outing carers think the person may enjoy. Often the word "No" seems to be the only way the individual feels they can assert themselves and express their anger at their situation, even if they really mean to say "yes".

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?

There have been many different responses to dementia, but these seem to relate to an individual's personal experiences. Those who have had little or no contact with dementia tend to be less understanding.

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

Not sure

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?

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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?

Depends on an individual's wishes. These still need to be respected, but if there is no treatment available how will this distressing news help them? Carers / family may feel they need to be aware and should also feel able to ask for help if they need it. The individual may well suspect "memory problems" and be in denial. A diagnosis may be helpful for carers when requesting help and support.

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?

Old people generally tend to be dismissed as a nuisance, not contributing economically, and not beautiful in our image obsessed culture. Sometimes it seems dementia can justify this dismissal. Families who have experience of dementia tend to be caring and concerned. It is something to be hidden away so society can pretend it's not happening.

We need a realistic portrayal of dementia, the issues it raises for families, employers or carers, and society as a whole. While it is probably hard to promote a positive image, people like Terry Pratchett have done a lot to raise awareness of the condition. Dementia may return someone to the very basic needs of an infant, but they are still an individual human being, with feelings, thoughts and wishes, and these need to be respected as far as possible even if they cannot communicate. More "ambassadors" for those with dementia might help reduce the fear and shame disgust that dementia can provoke.

Hospital carers and domiciliary workers need a far better understanding of dementia so they can give care with respect for an individual without losing patience and resorting to physical constraints, and hostility.

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

There is a real fear around dementia and the loss of control that will arise. There are fears that the individual will be forcibly removed from their home and put into a care home where they will be abused as a matter of course. There is a fear that no one will be their advocate when they are "in the system" because the state knows best and their individual wishes will be over ridden.

This can prevent individuals with dementia and their families from seeking medical help and a diagnosis which could be beneficial if more support / medication could be made available.

There is also a genuine fear that they will not be given proper medical treatment for physical problems such as cancer as it won't be considered worthwhile to treat someone who has dementia.

Society generally tends to fear mental illness, old age, and dementia encompasses both of these fears. Work needs to be done around removing the stigma for those who suffer, and also for those who work in the area as medical professionals, domiciliary workers and carers.

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

Yes as this can reduce the general fear of a condition that is hidden away in at home or in care homes. Perhaps if feasible encourage contact between older people and young people – perhaps through reminiscence projects / more outings for people with dementia in care homes if this is appropriate.

Person-centred care and personal identity

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

Yes in that it should be centred around the individuals circumstances, needs wishes rather than the Doctor knows best approach. There is a saying that “when you have seen one person with dementia, you have seen one person with dementia.” If someone has expressed particular wishes about their medical care, living arrangements etc before their dementia is too advanced these should be respected, but bear in mind an individual may change their mind, and they may have difficulty expressing their new wishes, but facial expressions and other non-verbal communication should be used to inform any treatment, together the views of their family / carers. Medical professionals and carers should always remember to treat the sufferer with dignity and respect.

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

From what I have seen dementia appear to reduce the social inhibitions that make us conform to societies rules. The person’s good and bad characteristics tend to be exaggerated so they become a caricature of their former selves, perhaps they way they were during their “terrible two” stage as a toddler.

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?

Its very difficult for families and friends to understand, particularly before a diagnosis. Once people know what has happened the changes can be understood, but it is incredibly distressing for family. The role reversal between parent and child is very difficult. It is immensely difficult dealing with the constant behavioural problems with patience 24 hours a day. More educational support for carers about the changes they can expect to see might help, together with general advice might help to reduce the sense of isolation.

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?

If the person has a family who knows how the individual felt about these issues before the onset of dementia this can be a starting point, as can the aim of minimising suffering.

It is very difficult trying to give someone day to day care that they would always have wanted – perhaps a bath for someone who has had high standards of cleanliness, but who gets violent and shouts when a bath or shower is attempted.

In terms of medical care, perhaps treating someone with a terminal condition as opposed to letting nature take its course this is very difficult for a family member to decide – even when they know the views that used to be held by the individual.

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

In this case the individual may need some guidance, and perhaps joint decisions should be made with the individual being involved to some extent. This would probably be difficult to implement though. One can only go on the views the person expressed before they developed dementia, and use these as a starting point, but bear in mind these may need to be overridden if they are not medically appropriate. Look at the longer term effects of the proposed treatment – will they reduce suffering or increase it. Sometimes the only person who can make an informed decision is a doctor / medical professional as they are the only ones who understand the complexity of the issues and the implications for the future.

The behaviour resulting from dementia may mean someone says “no” when they don't mean “no” to treatment, but perhaps “no” to their medical condition. Sometimes too much weight is given to the individuals response, which is not necessarily for the best medically or socially.

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

It shouldn't in an ideal world. But when care has to be rationed it seems inevitable that an existing degenerative condition such as dementia will play a part in decision making. A very distressing issue is pain relief. This should be available to people with dementia, even when they are unable to communicate their pain by asking for pain relief or pressing a button.

If the individual expressed wishes about this before they developed dementia these should be considered as part of the decision making process.

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?

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?

#### 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?

Yes, when one has to tell them of something upsetting from their past that they have forgotten – for example that their parents have died. The individual may become very distressed as it's as though they heard this news for the first time. Eventually it is less distressing for everyone if one says that their parents are away just now. The question is then forgotten quietly. This may not be ideal or ethical, but carers and families and the individual with dementia may not be able to deal with the extra distress.

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?

Common sense should be used, and balance between respect for the individual, and their protection. There comes a point when it is not sensible for someone to drive a car or go out on their own.

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?

This depends on the method of restraint. It is sensible for car keys to be taken away, however much the individual complains. Installing a key safe / locking external doors to prevent wandering again protects the individual and makes life easier for carers, and safer for the individual. Is it really sensible for someone to start wandering around outside at 2am because

their dementia means they are confused and cannot distinguish between day and night.

Chemical constraints / sedatives can have a place but only with ethical medical supervision – not just to make life easier for carers / care staff. Tying someone up or putting them somewhere they are physically unable to move from must always be unacceptable.

A lot more needs to be done in the area of education for carers / domiciliary workers. Often a situation can be diffused without the need for restraints or drugs if people have greater understanding for the illness and how to handle difficult behaviour resulting from dementia.

- 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 appear to give dementia sufferers the appearance of more independence, and to allow carers to be more relaxed about allowing freedoms they may have been concerned about in the past. If a tracking device means an individual is not kept locked up, but is allowed the freedom to go where they chose within certain parameters to keep them safe, this seems to be beneficial. Common sense needs to be applied.

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

As the population ages perhaps we need to have a national debate on what care is provided by the state and what is paid for by individuals with the means to pay. At the moment there is a random state of affairs where all medical care is free, but all care relating to mental illness / dementia must be paid for entirely by the individual after means testing. This arbitrary distinction will need to be re-examined, and perhaps everyone has to contribute more to their long term care in old age, whether the illness is physical or mental.

#### 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?

Carers need a lot more support, and there needs to be a recognition that not everyone is a suitable carer. It does not follow that just because one is a daughter one is automatically going to leave paid work, give up the opportunity to have children, sell one's house, leave one's social circle and move in to care for the elderly parent. This assumption is not made

about sons, but there is an unspoken assumption that women are carers and must take on this role 100%

If someone has dementia it is likely that more than one person will be needed to provide appropriate care, and families need respite from the 24 hour a day care regime. Greater investment is needed in providing personal care to help families.

Employers need to be more aware that carers look after adults as well as children, and similar safeguards need to be in place as for employees looking after children.

- 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?

The needs of carers need to be considered as well as the needs of the individual with dementia. Sometime compromise is needed.

- 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 a person has said they will never go into a home, and that their child will look after them at home, this cannot always be a realistic expectation.

If a couple are both elderly and have different needs everything should be done to keep them together.

- 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?

Carers need as much information as possible to make informed decisions. If someone is incapable of making decisions for themselves then their family (assuming they are on good terms and can be trusted to act in the individual's best interest) need the same information that would be given to the person concerned. There may be tensions within families which will complicate this issue.

## Research

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

A cure would be wonderful but does not seem realistic. Research around ways to mitigate the effects of dementia whether through drugs to slow

the process or education around managing behaviour rather than resorting to drugs / constraints.

- 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?

This depends on whether the individual held views on this before they developed dementia, and also on the nature of the research. People should not be used as guinea pigs because they are unable to protest. Families will need to make the decision based on the risks presented to them by the medical practitioners. Ultimately the research should have no negative effect on the individual, and they should not be put in a position where they feel afraid or in pain.

- 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?

Other issues

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

Remember that an individual with dementia can still be capable of manipulating a situation, and that their behaviour is not always rational.

Often medical staff give too much weight to the views of the individual – for example my mother became bed bound for a few weeks on going into hospital. Physiotherapy was arranged to help to get her mobile again. She was denied help because no one could give her any physical support, so no one could help her out of her chair, and also because she was in some pain, and said “no”. She never walked again.

Remember that carers may not always have the best interests of the individual at heart.

Compromises will always need to be made, and common sense should be applied.

When diagnosing someone with dementia, the standard questions asked by the GP are very easy for an intelligent person with a good education. This can be frustrating for families who are told there is nothing wrong, when they are sure there is a problem, and if drugs are an appropriate treatment, there is a delay and subsequent avoidable deterioration in the condition.