

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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Response to the full version

### **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?**

#### **Impact on Person diagnosed with dementia:**

the loss of skills erodes independence and increases dependence on others, it is frightening, and information given is patchy

the biggest impact is in the early stages when there is some insight

#### **Impact on Families/carers :**

- i) increasing reliance on families from person with dementia to remind and prompt about every day tasks eg. How to use a piece of household equipment such as a washing machine that they would previously have used on a daily basis because of loss of sequencing skills.
- ii) It is distressing for families to see a change in the person and the subsequent changing roles in the family.
- iii) often in the early stages of dementia the person is reluctant to acknowledge the changes in their abilities or behaviour and this can be frustrating for close family and carers. The person with dementia may refuse to visit professionals such as a GP or accept a referral to a memory clinic.

#### **Impact on Society :**

as the number of older people increases it is predicted that the numbers of those with dementia will increase. This will put pressure on the services and thought will need to be given who and how to best provide services/support/information. Additional funding will be required - whether this is state funds or personal insurance.

On a more individual basis the impact of the 'strange behaviour' of someone with dementia whilst out and about could trigger negative responses from the public as they don't know how to respond.

**Q1 (cont) What kind of support is needed most by people with dementia and those caring for them?**

**Support**

The most common thing we hear is that the person or carer is not given information at the point of diagnosis either by the specialist nurse or consultant. No-one seems to think that the GP should give out information and they rarely do so.

There needs to be a variety of services including benefits advice, access to information about the condition from specialist workers such as community psychiatric nurses and social workers, carers need access to respite in form of day care or residential care or direct payments to purchase care, links with carer support networks. Health and Social Care to provide joined up services.

Support needed will vary on individual circumstances and the stage that the dementia has reached. Organisations need to be able to respond on an individual basis with a variety of approaches. Services need to promote inclusion, acceptance and continuation of chosen occupation.

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

Medical treatment – eg. decisions about use of anti-biotics to treat infection – families making best interest decisions and not always objective.

Restriction – eg. Preventing going out of buildings because of potential risks – this can be because of anxiety of others such as family or care staff.

Use of telecare/assistive technology in people's homes. – person with dementia does not always have capacity to make an informed decision and family may feel it is in their best interests to install often to meet their own anxieties.

Taking someone to a residential/nursing home when that is the 'best interest' decision but the person does not want to go and we have to use all our powers of persuasion or distraction to get them there

**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?**

We have worked with service users from a variety of backgrounds - the problems raised by those with dementia and their families/carers have always been similar.

One issue has been communication – some persons with dementia whose first language is not English have an added hurdle to jump in communicating their needs. Some service users who may have had a good working knowledge of English and conversed very competently may revert to using their first language as their dementia progresses. This has implications for training and availability of staff/carers who speak both their first and second languages.

Many of the memory tests that are used to assess persons are very culturally biased so may not accurately reflect the level of memory loss eg. if asked date of birth – not all ethnic groups have a precise record or knowledge of their birth so failure to give accurate date would not necessarily indicate a problem. Tests should be culturally sensitive.

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

Detailed individual care plans are required to ensure all needs are addressed including cultural needs – as the service user is not always able to express these it is important to have workers who are well trained in cultural diversity plus time should be spent talking to family who may be able to contribute to building a picture of individual needs – this may include such things as diet, religious festivals, dress.

**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?**

No detailed knowledge.

**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?**

Any symptoms should be assessed a.s.a.p to eliminate a physical cause which could be treated – the downside of this is that if no physical cause found then a diagnosis of dementia may be made which could be distressing to the person and family. On balance an early diagnosis would probably be preferable as long as back up services available to offer support and advice eg. CPN, social work, voluntary sector–eg. Alzheimers society.

However, we should be wary of GP's making early 'guesses' and raising anxiety when it is not appropriate

**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?**

Many people are frightened of developing dementia – need to 'educate' – one way would be to use prominent people who have been diagnosed with condition such as Terry Pratchett to reduce anxieties of others.

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

There is still a general reluctance by some to seek help when they suspect they may have dementia. It is viewed as a mental health problem especially as they will normally be referred to a psychiatrist. It is not easy to break through these barriers. The stigma attached to Dementia is inextricably linked to that of mental health services in general – we can't deal with the one without the other.

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

The aim should always be to include as far as possible – In social care 'registration rules' can restrict the mixing of those with and without dementia together. It should be possible to have day care and residential settings where groups can mix with the correct support from trained staff.

We need to include rather than exclude – eg. Not to automatically segregate those with dementia from others because of 'registration' requirements in care settings. When in the earlier stages people with dementia remain better orientated and maximise memory skills when with others with more intact mental skills.

Extension of Use of direct payments and individualised budgets should make inclusion in the community more possible.

We have a successful voluntary group whose aim is to keep people part of their local community and they regularly use community facilities – they manage this because they have a good ratio of volunteers to people who need the special support.

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

Everyone is unique and has an individual set of needs therefore person centred care is essential. There needs to be as wide a selection of services available as possible to allow choice – to see the person first rather than the disability.

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

Although dementia gradually erodes the mental faculties the person's identity lives on – as the disease progresses this may become more in the memories of close family members – but the individual will still be a man or woman , a mother /father, grandparent, be a member of a faith group - Christian/Jewish/Muslim etc. This highlights the importance of comprehensive social histories being completed and being used by carers looking after people in the later stages of dementia. Even in the later stages of dementia senses such as smell and taste remain therefore previous likes and dislikes which all make up identity are still there and important.

However, it is a commonly made statement – 's/he is no longer the person I knew' and it requires a high level of understanding, commitment and dedication to be able to maintain an emotional relationship with a family member and this in turn requires help and support from the 'experts' whoever they are in one's own network.

**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?**

Although it is always important to respect previous values and wishes there has to be a recognition of changing situations – if a husband promises a wife who is in the early stages of dementia that he will never put her in a 'home' and then he struggles to manage difficult behaviours that may develop at a later stage it may be there has to be a re-assessment of the situation –this can cause conflicts within families – different members may have different ideas about how to manage these changes. There is the issue of medication to manage behaviours with the accompanying 'side effects' for one.

**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?**

Decisions cannot be made in isolation and need to be made only after considering opinions of all involved. A person's past wishes should be acknowledged but it may be that their present condition puts them at

such a great risk that these need to now be given lower importance. One cannot exclude the other and it is this careful balance that makes the decision making so much more difficult and important.

I would hate for my expressed wishes to be ignored especially if they had been well thought out with a consideration for safety risk etc. but at the same time the people who are making the best interest decision have to be well trained ( if professionals) or well chosen as in Lasting power of attorney so it is so important to encourage people to do this in advance.

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

To take the least restrictive option – to repeat mental capacity test at suitable intervals – get second opinion – depends on consequences of the issue being discussed – the level of risk.

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

The diagnosis in itself is not the issue – it is the capacity to make decisions for oneself. See answers about best interests.

We would need to look at the treatment – how traumatic would it be to the person? how long would it prolong life? What would be the improvement to the quality of life? Also need to know about previous wishes about treatment.– they may still have an insight into situation.

People with dementia should not automatically be denied treatment which would extend life.

**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?**

In general welfare attorneys are an excellent idea as they are appointed by the individual when they are well and have full mental capacity. They should have a good understanding of the wishes of the person. However there needs to be some form of arbitration process when there are disagreements between health professionals and the welfare attorney– perhaps the use of independent advocates to contribute to the decision process – so that a final decision can be made.

**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?**

I feel it is a personal choice about making advance directives – for some people with very strong views then it is important – for others they prefer others to make decisions for them - it is impossible to know the impact of a decision/directive made many years before the event occurs. People should at least be given information about advance directives so they can make the decision – a bit like a will – some do it and some don't.

**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?**

The Mental Capacity Act has been very beneficial - it has given a legal structure to the decision making process – it has given clear responsibilities and guidance and as long as the professionals involved have had thorough training and the public are given adequate information about it, it will be beneficial. The main downside is that the Lasting POA costs much more than the previous EPOA which may put people off making the arrangements for themselves.

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

As a general principle I feel we should always be truthful but there are situations where it may cause so much distress that a best interest decision would have to be made – eg. we feel we should inform a person of a close relatives' death but if they cannot remember this and keep asking where that person is a decision has to be made as to whether it would cause more distress by telling them or by distracting them away from the question. My personal view is that we should not cause more distress than necessary and I would not keep telling a person that their loved one is dead. There comes a point when conversation is more important than cold truth and a conversation about a person is more constructive than living through a bereavement day after day.

**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?**

You cannot generalise!! – some families err on the side of caution because of their own anxieties, others may seem not to care or not agree to support which would reduce risk . With the development of telecare etc [despite the ethical dilemmas] this may make it possible to reduce risk and give greater freedom to individuals .

In general I would say as social workers we are sometimes over cautious not just to protect the person but also because everyone is 'frightened' of the come back if something catastrophic happens – eg a lady with dementia wandered and was killed trying to cross a railway line. She had left her home after her evening carer had visited and seen her to bed for the night – if a telecare system had been installed to identify that she had left the property and someone had quickly responded would this have prevented the accident? If she had previously been admitted to residential care which would have been against the wishes of herself and her family this may have prevented the accident. This event happened before the implementation of the Mental Capacity act which could now be used as an aid to making decisions about taking individual risks.

**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?**

There are occasions when some form of restraint has to be allowed to protect both the person with dementia and their carers .The Mental Capacity Act has made it easier to assess individual risks around restraints. Any form of restraint used by professionals would need to have a written assessment in the care plan.

Carers use of restraint would tend to be 'locking someone in' to prevent 'wandering'. It could be argued that it is a decision taken in the person's best interests as long as it does not lead to permanent limits to the person's freedom, social inclusion, need for fresh air etc.

**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?**

It would be helpful for carers to have access to training sessions, internet sites, written leaflets, access to specialist nurses to assist them in their role and the ethical dilemmas they may encounter.

**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?**

Any new technology will take time to introduce and gain acceptance. There are issues about installing equipment and monitoring people who cannot give their informed consent. It feels like 'Big Brother' and that it invades people's privacy and liberty. However if the equipment enables a person to remain in the community rather than be admitted to residential care perhaps it is a price worth paying. It is another 'best interests' decision. As it is new it will take time for people to accept and use.

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

People with dementia require the same services as the rest of the population – ie. access to all services they may need including health and social care. As they may not be able to access these without assistance from others we need to ensure advocacy services are available if they have no family/carers to support.

The needs of carers/families.- they have the right to expect that their relative will be treated with the same respect and dignity as any other person.

**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?**

There needs to be a process in which cases are monitored and reviewed on a regular basis so that potential conflicts are highlighted before they reach crisis situations – this could be by a social worker or CPN or similar professional – and if necessary unresolved issues could be taken to a group meeting for discussion and decision. The Mental Capacity Act has a role to play as it allows 'best interests' if the person lacks capacity in making a specific decision. Carers' assessments recognise that carers have needs of their own.

**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?**

Professionals are often in the middle – they can see the stresses on the families/carers but at the same time want to protect the rights of the person with dementia. We have a duty towards all vulnerable people. On occasions it is useful for the person with dementia to have a different case worker so those involved in the conflict have their opinions/wishes

fairly represented. Carer support groups play a big part in this too. Where the situation is very complex case conferences enable people to hear each other and discuss options so that a consensus can be reached. I have no experience of an unresolved conflict – we have always managed it albeit sometimes slowly.

**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?**

It is not possible to view the person in isolation – eg. If the main carer is an elderly spouse who has poor health and the stress of caring for the person with dementia is detrimental to their health then this has to be important too. Ongoing support by the social worker or other case worker can play a part in achieving an outcome that meets the needs of the couple/household. It has led to the practice of persuasion to accept a service/solution where all else fails which again can now be part of the MCA capacity/best interests process. None of this is done without a due process of talking, listening, trying to agree on a consensus.

**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?**

Confidentiality is very important so information should only be shared if the person has given permission - however it may not be possible for the person with dementia to give this permission. At this point it becomes a judgement about how much information should be shared with family. Then it becomes important to know previous involvement and support so you can act in best interests.– I know of both types of occasions ie. Too much or too little information being given. Decisions should be taken in discussion with others so a consensus is reached .Decisions should be logged so there is a record .

## **Research**

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

Greater understanding of causes and origins of dementias.

Impact on lives of person with dementia and their carers/families.

Research should look at the effectiveness of new technologies in supporting people with dementia in the community.

Research in to how other countries are managing the care of those with dementia to see if there approaches we can try.

**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 the type of research and how intrusive it is in their lives.

Without research of some kind it would be impossible to make progress in the treatment and management of the condition .

Safeguards would include decisions being taken by a number of persons rather than one person alone.

**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?**

Unaware of any issues.

#### **Other issues**

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

Not aware of any other issues.

Response to the shortened version

Nuffield Dementia Research – Ethics

Q2 I think that religion, culture and background can make a huge difference on the impact of dementia. A person's religion may contribute to how well they are able to cope with challenging situations and the religious community may provide comfort and support to sufferers and carers. In some cultures, dementia may be accepted as part of the ageing process, whereas in others be viewed as insanity and something to be ashamed of. Likewise, family background plays a big part in the level of support and care available (or not) for the sufferer. If family dynamics are such that no support is possible, the dementia sufferer may experience isolation and will rely on assistance of formal services for support. If the person has been in an abusive relationship prior to the onset of dementia it is possible that their carer could put their health, safety and well being at risk.

Q3 I think a diagnosis of dementia should be made when;

- a) a person presents with the recognised symptoms and after all other medical conditions with similar symptoms are ruled out.
- b) After thorough cognitive assessments and scans have been completed by health professionals qualified to do so.
- c) Diagnosis should also depend very much on the wishes of the sufferer e.g when a person has sought medical attention and wants to know what is wrong.

Q4 Yes, for the most part person centred care is helpful. In my opinion, any approach to healthcare that takes the thoughts, feelings, needs and desires of the individual and places them at the centre of their care has to be a positive thing. The idea of person centred care is one where the person needing care has choice and control over the care they receive, maintains autonomy and has services that fit to their needs, rather than the other way round. It is also helpful in that the individual is viewed from a biopsychosocial model of healthcare rather than the outdated medical model.

Q5 Define "themselves"! I think that dementia causes regression to such an extent that those people around the sufferer no longer recognise the person they once knew and to that end, yes I believe that they do stop being "themselves". I also think that some behavioural aspects of dementia may result in the sufferer displaying behaviour that they never would have done prior to the onset of the disease. However, I would still argue that the person is "themselves", just at a different time in their life.

Q6 I think that society in the UK is generally fearful of dementia, It is the disease (apart from cancer) that no one wants to develop in older age and when faced with the reality of dementia, would rather brush it be "under the carpet". I

also think that a large proportion of society perceives someone with dementia as mad and who has lost their mind even if they are not in the late stages of the disease. I think that society sees dementia as purely a disease that affects older people and is largely unaware that it can affect younger people too.

I believe we need more people like Terry Pratchett (i.e high profile) who suffer with dementia to speak out through the media in order to show people that there is life after diagnosis. I also believe that schools and younger people can help raise awareness in the community through fundraising, poster designing etc to educate communities and promote better understanding of dementia within communities

Q7 Yes. Just because a person has a diagnosis of dementia it does not mean they have lost the wealth of knowledge and experience their life has given them. Acceptance is key and I believe that inclusion and acceptance of the community helps to educate people, facilitates unconditional positive regard and helps maintain the health and safety of the sufferer. How a person is included in the everyday life of communities depends upon; a) how much the sufferer was in the past and wants to be in the future, b) the type of community and c) how much support the person has from family, friends and carers. I think that the time for a person to cease to participate in everyday community life is when it becomes distressing and fearful for the individual.

Q8 I think the government owes a high level of good quality care and support for sufferers and their carers / families. I think that the government owes these people places to go in order to socialise, money to fund organisations that support people. I also think that the government owes people the best possible medical attention and medication available without the added pressure of having to fight for the right. I think the amount of money paid to the government by these people over the years far exceeds the cost of care in later life and that, by not providing the above, the government is failing in its duty of care.

Q11 I think that people should be encouraged to write advance directives so that, in the event that they cannot speak for themselves there is a legal document stating their original choices. However, I also think that people need to be made aware that the advance directive may not be the single decision maker in certain cases i.e if a person has made an advance directive prior to illness and changes their mind at a later stage when capacity is in question, there should be the involvement of family, carers, health professional and advocates etc to reach a final decision.

Q12 I think they need to seek 3<sup>rd</sup> party involvement either for a 2<sup>nd</sup> opinion or as a mediator between the two. Ultimately it is the person with dementia whose wishes should be adhered to, even if it does go against either side's personal or professional opinion.

Q13 I think there are times when insisting on telling a person with dementia the truth can cause more distress. If a person with dementia is repeatedly talking about their parents and asking when they will be coming to pick them up, I believe it is better to give some comfort by saying "Maybe another day" or some such like rather than "Your parents are dead and have been for 25 years". However, I do believe that honesty without unnecessary distress is paramount in all cases.

Q14 I think it depends upon the context of the action desired and the stage of dementia. I think it is usually carers that do not know about dementia that become over or under anxious about the risks i.e a carer deciding to go out for the day believing it is fine to leave the person alone because that's what they've always done, may not truly understand the nature of the disease and how it can affect rational thought or insight of the sufferer. I think that unless the person could be at serious risk of injuring themselves or other people, everybody has a right to pursue chosen activities in order to maintain health, well being and autonomy for as long as possible.

Q15 I think this is a very controversial subject. If there is no other option and all other avenues have been explored to prevent serious risk of injury to the person or others, then some form of restraint will have to be applied. However I believe that only people with a high degree of training in this area should be permitted to restrain a person with dementia. I also believe that there should be records proving that restraint is justified and all other means of prevention have been tried first.

Q16 Yes I do think that some assistive technology does raise general ethical issues. For example, systems can be put into place covertly in a person's living environment, thus removing choice and potentially freedom. I believe that systems such as tagging may have a place in protecting the health and safety of someone who becomes disorientated and wanders at night. But I also think that this can be seen as a quick fix, removes autonomy from the individual and may mean that the causes of wandering are not addressed. It also removes responsibility from the government for providing person to person care, thereby resulting in a money saving exercise. It can also lead the dementia sufferer to become a prisoner in their own home and be open to abuse.

Q17 Healthcare professionals can help by ensuring that the carer's needs are recognised through assessment and the wider therapeutic relationship with both carer and client. Professionals should be aware of statutory and non statutory organisations that are available and who can help support the carer to meet their needs whilst also meeting the different needs of the dementia sufferer. Professionals have a wealth of knowledge about how to access varying services, how to support people with conflicting needs and how to gain financial support for the carer to continue in their role.

Q18 I think the answers to this depend on the professional involved and how aware they are about the rights of individuals, their families and carers with regard to the disclosure of information. Unfortunately, if a professional believes that it is too soon after diagnosis to provide all the information about the progression of dementia, the family may be left with a struggle to come to terms with any changes that may occur. Likewise, a professional may divulge information to a family member that has not been told to the client or a family member could make demands on health professionals to give them information about the client. Ultimately, there still seems to be some uncertainty (in some professionals and families) surrounding the confidentiality, freedom of information and data protection legislation.

Q19 I think research into dementia should try to find any previously unknown causes, with a view to preventing or delaying the onset of the disease. I also think research into effective drugs that can help delay symptoms and preserve the life of sufferers should be ongoing. I think that more research into activities and their effect on the general health and well being of dementia sufferers would be beneficial as well as more research into the effects of the disease on carers. Funding should be allocated in the same way that cancer research is funded i.e equally if we are to progress and raise awareness of dementia.

Q20 I think that unless previously agreed by an individual before capacity is lost, no drugs trials should be undertaken. However, If research is looking at the experience of living with dementia, changes in the progression of the disease or quality of life etc, then I believe that as long as consent has been gained from family or welfare attorney and strict code of ethics and professional conduct are adhered to, the person could be involved.

If I was conducting research I would contact the local governing body for guidance and approval regarding funding (if required) ethical considerations and capacity. I would ensure that a clear explanation was provided and that approval was gained from the Alzheimers Association. I would write to all parties concerned to request permission, provide full details of how the research would be carried out and what I was hoping to achieve. I would ensure that all records were anonymous and held no personal details, that the research proposal was hoping to gather sufficient evidence to improve practice (and care) and that all information gathered would be made available once the research was complete.

Q21 I think that the issue of abuse should be considered in relation to dementia. There is evidence that shows the prevalence of abuse to dementia sufferers and older people by their family, carers and health professionals. Although this does not mean ALL of the people involved in dementia care are abusers, I think it would be useful to find out quite how much health professionals, family and carers know about how to react and what to do if they suspect that someone who lacks mental capacity is being abused.

