

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.

National Prion Clinic

QUESTIONS ANSWERED:

Q1

ANSWER:

The experience of any illness is unique to every person that is affected. What has the greatest impact on a person with dementia and their families will depend on the severity and rate of onset of the symptom, and the social structure they live in. Often for patients the loss of memory and resulting confusion can have the greatest impact on their lives, preventing them from working or helping around the house, which can lead to feelings of worthlessness and that they are a burden to loved ones. Families seem to struggle most with a change in personality in their loved one; a lack of interest in others and emotion, and the change this causes to relationships. There is a feeling of the loss of the person they love. Society's mostly negative view of dementia and the stigma attached to it can be incredibly difficult for affected people and families, and can influence their access to care and services. The impact on society is largely financial; with the number of people affected by dementia growing every year the cost of caring for people to the NHS is growing. There is a nationwide problem of the lack of provision of care for younger people with dementia, which impacts on the people and families affected and other services. Support: People need support at times to diagnosis - this is crucial to their response to the diagnosis and can impact their experience of dementia for the rest of the course of the illness. Care provided needs to be holistic and multidisciplinary - looking at every aspect of the person to maximise their independence and maintain their individuality: reminiscence therapy, life history work. Regular support and respite is needed for family carers, so they do not become overwhelmed and isolated. Often they feel angry, guilty, and are grieving for the person they have lost. These feelings need to be validated. Formal carers need a chance to meet regularly to reflect and share experiences. Unqualified carers caring for people in their own homes are often isolated, and do not have the opportunity to discuss problems, or share positive experiences. At the National Prion Clinic we have helped establish regular support sessions for carers which have helped promote a creative approach to care, and given carers an opportunity to share with each other. Ideally carers should be paid for the time they attend these sessions.

Q2

ANSWER:

At the National Prion Clinic we frequently work with people with dementia who are under 65. Very often people with young onset dementia lose their cognitive capacity at an early age. There are few external care home providers for people

with early onset dementia. This means that people often end up being cared for in less than ideal conditions or surroundings. The aim of care should be to be able to provide a bright stimulating environment to encourage a quality of life that the patient deserves. However in reality they are often placed in an older environment which they find difficult to adapt to. Often the activities and day trips, the music and T.V. programmes put on in communal areas, and even the food are unsuitable for a younger age group. We have an ethical duty of care to these patients yet funding is such that people very often don't get the chance to maximise their potential within a care setting. A closer look needs to be taken at the care needs of the country and provide a variety of care settings that enable patients to achieve a good quality of life.

Q4

ANSWER:

All care should be tailored towards the individual needs of a patient regardless of the setting that care is taking place in. When care is provided in a multi-cultural context then all staff should be appropriately trained in potential multi-cultural issues and there should be adequate staffing numbers to support patient needs and to avoid potential conflict. Most of us carry some thoughts of prejudice even if we are not conscious of it. The progression of dementia very often brings with it a degree of inhibition. Because of this prejudice we may carry when not disinherited often becomes apparent in Dementia, it is important that patients are adequately supported in their environment to have individual opinions that do not end up hurting other people.

Q3

ANSWER:

Understanding of and attitude towards disease varies widely from person to person and is influenced by their cultural and social backgrounds. In the UK dementia appears to be widely viewed as an inevitable part of old age. People with a religious belief often cope with illness and death more positively than those without. This can be partly to do with a belief in an afterlife, and that death is not the end, and partly to do with the additional social support network people have access to through their faith. Peoples ethnic and cultural background can have an impact on their access to services, and therefore diagnosis. Families have different reactions to symptoms. For example a strict Muslim family may be much more distressed by an female relative showing uninhibited behaviour than a British non-religious family. Cultural backgrounds will also influence the type of care people receive and where. Typically British families now are small units, without close links to a support network of extended family, as apposed to families from other cultures who have have several generations living in the same house, and are more likely to want to care for an unwell relative at home.

Q5

ANSWER:**Q6****ANSWER:**

Emphasis should not be put so much on 'when' the right time to make a diagnosis is, as this will differ from person to person, but giving the diagnosis in the right way, and with a structured follow up programme and support network. As with all illnesses where a differential diagnosis is possible, all the possible should be discussed with the affected person and their families (where appropriate) and ruled out via thorough investigation. Each individual case must be judged in context: the effects of the symptoms are having on the affected person and their families, the risk of harm to the person or others, and whether the person is aware of their symptoms and wants to seek the cause of them. As viable treatments become available priorities are likely to be in favour of an early a diagnosis as possible.

Q8**ANSWER:**

The negative stigma associated with dementia can lead to affected people being marginalised within their community, or moved to residential and nursing homes against their wishes as they are perceived to be a risk to themselves. This transition to an unfamiliar area often leads to patients becoming more acutely confused, scared, display more 'challenging behaviour', meaning they are more difficult to manage. Therefore the idea of people with dementia becoming aggressive and resistant to care is a self-fulfilling prophecy. A person's capacity to make decisions is often not properly assessed. Once a diagnosis of dementia is made, it often turns into a label and people are viewed as a group of symptoms rather than an individual with complex needs. Dementia has always carried stigma in this country. Historically people with Dementia were locked up in an asylum along with alcoholics and local petty thieves. This unfortunate traditional coping strategy used by so many to hide the illnesses of their loved ones and avoid the label of madness has had a huge impact on how society view dementia today. It has almost become acceptable to have dementia if you are old. When this happens people see it as a natural progression of age and not something to be ashamed of. However if you are unfortunate enough to develop dementia under the age of sixty then unfortunately your acceptance by society can be very different. Even care provision is different. A Family might not have access to the best possible care if they are afraid to let the local community know of their needs.

Q7**ANSWER:**

In the UK the negative attitude towards dementia is remains inherent in individuals, communities and society as a whole. It is often seen as an inevitable part of old age, and that nothing can be done for the affected individual, leaving them isolated and often institutionalised. Better understanding in healthcare professionals can be promoted through training and education. If Dementia was perceived as a specialism (like cardiac or oncology) then healthcare professionals would be motivated to work in that area, and be keen to learn new skills. Positive examples of the experience of dementia could be promoted through the media and television. Soap Operas for example often tackle difficult issues such as domestic violence, and have a large and wide ranging audience. Changes in society have meant that many people grow up without older relatives or any experience of being with and talking to older generations, which can lead to misunderstanding and stereotyping. Potentially school programmes such as work experience could give young people the opportunity to work with people of dementia, and help to break down some of the myths and barriers. There is little knowledge and experience amongst professionals or service provision for younger people with dementia, and awareness of their unique needs must be raised.

Q9

ANSWER:

Yes. Care should be given with the aim of maximising people's independence and individuality. People with dementia should have access to schemes such as palliative rehabilitation programmes so they can continue to perform the tasks they are able to for as long as possible. Any person, suffering from dementia or otherwise, will lose skills and abilities if they are not practiced. Involvement in community life, such as going shopping, coffee mornings, having the opportunity to take part in gardening schemes, physical activities, and a range of other things will help improve the Quality of Life for people with dementia. Having an active role in the community and interacting with other community members will also help reduce the stigma attached to dementia.

Q10

ANSWER:

Person centred care is theoretical concept, which is frequently over-used and needs qualification in its application. The concept originated with Tom Kitwood and since then many other approaches following the same ideas have been placed under the person-centred care umbrella. Person-centred care covers everything from detailed day-to-day care planning to environmental design. Graham Stokes defines person-centred care as not dismissing a person's behaviour as 'just part of the dementia' but looking closely into the person's background, their likes and dislikes, religious views etc, so see if there is a cause or explanation as to why someone may be behaving in a particular way. The concept is helpful when co-ordinating care for a person with dementia, as hopefully it leads professionals to look at the needs of the person as an

individual rather than as a group of symptoms when care planning and problem solving. Where possible affected people should be involved in their care planning, and person-centred care is facilitated by working with the person's family, researching their culture and background, and observing their responses to care and interventions in order to build up an understanding of that person. This requires a multidisciplinary approach.

Q11

ANSWER:

A person should never be identified purely by a condition or illness that they suffer from. However, frontal syndromes produce symptoms that can drastically alter a person's personality. Perceptual

Q12

ANSWER:

Radical changes in our moods and behaviour have an effect on all of our core relationships regardless of dementia. Many people think the love they have for each other will survive anything and this is often the case. However the implications of a once placid partner becoming violent or aggressive can have a huge impact on the person they are living with. Often they feel that they have lost the relationship they used to have and no longer recognise the person they once knew. Sometimes patients may express a wish not to go to a care home or hospital when the time comes and often this is a decision based on love and fear rather than practicality. People tend to feel guilty if they make decisions outside what was previously agreed even if they are no longer coping at home.

Q13

ANSWER:

This problem arises frequently, particularly where there is a strong element of denial in the affected person's presentation. Direct questioning about painful decisions such as respite and residential care often increase denial (and therefore lack of insight and capacity). I personally approach eliciting people's wishes through indirect questioning, for example if someone is saying no to residential care because they feel it is not the right time, "not yet", to ask what they would like to do when the time is right gives an idea of their long term wishes. Establishing what a person would want to happen if they stopped making the kinds of decisions that they would make now often reveals that they have thought about this. For example a young woman, married with two children refused to allow her husband to tell the rest of the family the diagnosis and the fact it is genetic. In answer to this question she answered that her husband would know what to do, freeing him to tell people behind her back without a sense that he had betrayed her wishes. This is a very challenging area that requires spending time with the affected person, and finding the most validating way to bring about the required changes that take into account the

needs of the affected person and their family. With our families there are often young children involved, whose needs are at odds with the wishes and feelings of the affected person. Advocacy, validation therapy and person centred care, and counseling in my experience have helped to resolve discrepancies in needs and wishes, but there is no single formula.

Q14

ANSWER:

Advocacy, validation therapy and person centred care, and counselling can help to resolve discrepancies in needs and wishes, but there is no single formula. There is often a grey area in terms of capacity as the symptoms of the dementias may fluctuate; structure, indirect questioning to reduce threat, validation of personhood and appropriate support can all improve capacity. Sometimes the stress of decision making can escalate symptoms too. Perhaps the most important issue is time. People with dementia cannot be rushed into decisions and a structured, clear approach by a person or persons the affected person trusts can go a long way towards bringing about resolution where the affected person is expressing wishes that are not in their or their families best interests.

Q15

ANSWER:

Life sustaining treatments such as PEG feeding and the use of antibiotics where there is no treatment to slow down or stop the disease process is something that preferably should be discussed with the affected person early in the disease process. The purpose of these treatments are not always purely to sustain life, but may for instance make taking medication easier where it is difficult to swallow tablets. Issues of stage of the disease, quality of life, whether the person is hungry and struggling to eat, the context in which the person is being cared for, and individual beliefs and wishes of affected person and their family. Ultimately the decision about medical treatments lies with the responsible physician, who would consider all these factors and act in the person's best interest. A diagnosis of dementia should not in itself be the deciding factor, rather quality of life, prognosis, comfort, and the needs of the family.

Q16

ANSWER:

In my experience there is a conflict of interest in the representation of people with dementia through solicitors. They are often acting for the family and not the person with dementia, unless an advance directive has been set up by the individual. In cases where there is compensation available, financial gain for the firm seems to work against the interests of the person with dementia and their family. IMCA's and advocates from the voluntary sector have been helpful in resolving conflicts of interest among family members where one person is

diagnosed with dementia.

Q17

ANSWER:

Advance directives are very helpful in understanding a person's thinking and wishes pre-morbidly. It can be difficult approaching this subject with people in the early stages of dementia, if they are in denial of their illness they will be very threatened by this process, and that of establishing Lasting Power of Attorney. It can be helpful to address this issue in a generic way with all family members taking part in the discussion, making their own wishes known, establishing their own Advance Directive and Lasting Power of attorney, naming the affected person as one of the appointed attorneys. Frequently this process becomes impossible as the disease has already progressed too far to make the process meaningful and legally binding. Unfortunately in some circumstances the appointed attorney makes decisions contrary to the expressed wishes of the affected person, and this is upheld legally.

Q18

ANSWER:

The Act can be viewed positively as it attempts to give people who are marginalised, a louder voice with which to speak. By providing a guide of how and by whom an individual should be assessed so that they may keep their personal right to choice as an individual, is an attempt to retain a human being's rights and independence for as long as possible. When dealing with dementia it is often all too quickly assumed that a person is unable to make decisions and thus, those decisions are made for them. For example: It may be easier and quicker for services to be arranged if a person has no choice as to what these are. It may be assumed that a person needs typical dementia services prematurely as they are classed as a 'type' of patient rather than an individual. Assessing the mental capacity of a patient and then listening to the patient's wishes can take time and may be more work for those involved, but ultimately the journey through the patient's illness will be personalised and more satisfying for all involved to know that it is the best possible care that as a group, they can provide

Q19

ANSWER:

Any decision made for a patient must be in the patient's best interests. This spans from clinical treatment to how a patient is communicated to. When communicating with people with Dementia it is often the way information is or situations are presented that is important. Any information must be given with respect to a patient's condition and with their ability to understand and process that information kept in mind. The truth should be told as far as possible, with the level of truth being carefully balanced with what is best for the patient's

wellbeing. All communication must be carefully considered. It would be wholly unacceptable for carers or healthcare professionals to withhold information or deliberately give misleading information (lie) in order to get the outcome most convenient for them. In patients whose short term memory is impaired, it may be necessary to reinforce the truth several times.

Q20

ANSWER:

With Decision making falls responsibility. When making a decision re a vulnerable individual, an assessment of risk must always be considered. What is tempting and often happens is to choose the 'safest' option in terms of someone's physical safety because the decision maker will be responsible and have to answer (often legally) if something goes wrong. This understandably cautious approach can all too easily be taken and compromise an individuals wishes. It is important therefore when considering a person's physical risks, to also consider the emotional risks of overprotection and how detrimental it can be to their overall health if their remaining freedom is prematurely taken away. A frequent example of this is when carers remain in the bathroom when assisting a patient to the toilet. If the affected person is capable of sitting in a chair without falling out, it is reasonable to assume they could sit on a toilet without slipping off, and have handrails or a frame placed in front of them as necessary. Many toileting problems arise from patients with dementia not realising they need assistance and not understanding why people watch them whilst using the toilet. A person's privacy and dignity should be paramount to their care at all times.

Q21

ANSWER:

Restraint should only be used to protect a person and attempt to keep them from harming themselves or others. It should also only be used if all other attempts to prevent a person harming themselves or another have been made. The decision should not be made by one individual but where possible by a group of people from different professional and non-professional backgrounds, especially by those who know the patient who can recognise the individual's change in behaviour and consequential need for restraint.

Q22

ANSWER:

A basic understanding of the ethical issues surrounding decision making in dementia care would be very useful for all involved in dementia care. This could be provided as a study day, or as part of a specialist training programme on dementia care. It could be included with a session on the Mental Capacity Act.

Q24

ANSWER:

The state has a duty of care to people with dementia in the same way they have a duty of care to all people who are affected by illness in this country. The NHS was set up on the principles: that it meet the needs of everyone, that it be free at the point of delivery, that it be based on clinical need, not ability to pay. The state has a duty to provide the investigations necessary for diagnosis, and the follow up support and care that a person affected needs. If a person with dementia meets the criteria for social services support and then continuing healthcare funding they should receive care packages from these agencies.

Q25**ANSWER:**

Regular meetings involving family members, carers and (where possible) the affected person, facilitated by a healthcare professional involved with the family (i.e. CPN, Social Worker) where conflicts/issues can be discussed, and problems solved. Careful planning can ensure that further conflict does not arise in the future. Healthcare professionals (HCPs) must act in the best interests of the affected person, but it is good practice to discuss all aspects of care with the person's family, and seek their assent for any interventions planned. Lasting Powers of Attorney can help in these cases. Where relationships or channels of communication between the affected person and their family has broken down, HCPs must act as an advocate for the affected person. All discussions must be handled sensitively, and time allocated for reflection on decisions made.

Q27**ANSWER:**

The best interest of the patient should always be at the centre of decision making. It is also important to look at the family as a unit particularly in relation to the role the patient made. If there are children involved who may be vulnerable then it is important that they are protected and secure. It is also important that support is available for them in the long term especially if they will be losing a close relative whose role can't be replaced.

Q26**ANSWER:**

As previously stated where possible professionals should facilitate discussions between the affected person and their family, with the aim of them 'sorting things out for themselves'. There are many ethical dilemmas that can arise, such as when a professional knows a family is embarking on a plan of care that would not have been acceptable to the affected person. It is important that the professional advocates for the affected person and makes what they believe their wishes were known to the rest of the multidisciplinary team.

Q28

ANSWER:

Sometimes professional caregivers' interpretation of patient confidentiality can be counter productive. It is helpful to be aware of relationships in families and the feelings of the individual concerned, but this is not always possible. Information that facilitates person centred care of the highest quality is important, and this is identified through spending time exploring the issues in caring for their relative.

Q29

ANSWER:

Better understanding of the causes of dementia Effectiveness of new medications Effectiveness of psycho-social interventions

Q30

ANSWER:

If the person has made an express wish to participate in research prior to them losing capacity then it is fine to proceed with the assent of a close relative who is aware of what their wishes would have been. If however the patient has expressed a wish not to be included in research then this should still stand. If no prior arrangement has been made and the closest relative is unsure of how the patient would have felt then the research should not proceed. When approaching affected people or relatives to enquire about research the aims and nature of the research should be fully explained, and supported with written information sheet. Relatives should give signed consent, and consent should be able to be withdrawn at anytime. Participation in research should not be a condition of access to services.

Q31

ANSWER:

No. The best interests of the patient and their families should always be held above participation in research, and the patients prior wishes (where known) should be upheld.