

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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## **QUESTIONS ANSWERED:**

### **Q1**

#### **ANSWER:**

For me the greatest impact was on our ability to socialise. In the early stages, the problems were loss of language, therefore inability to take part in conversation. This produced a huge sense of isolation and depression. This became even more acute when my husband became unsafe to leave on his own. The social needs of both the person with dementia and the carer must be met. The person with dementia must have a professional carer he can relate to, and enjoys being with, or it won't work. The timetable needs to be flexible, to allow the primary carer to pursue interests and hobbies. The carer needs to be regular and reliable, and trained to cope with a person with dementia. Day care centres need to be suitable for someone with dementia, with appropriate activities. Regular respite breaks should be available for those who need them. Those caring need support groups with others in the same position, and also the opportunity to meet and talk about other topics, so that their whole life does not revolve round dementia.

### **Q2**

#### **ANSWER:**

The rights of the individual to determine way of life and place of abode  
The right to privacy  
The right to dignity  
The right to decide on medical care  
Establishment of legal competence  
The right to decide on end of life care  
The rights of the individual v the rights of society

### **Q3**

#### **ANSWER:**

Culture and family background make a huge impact. Some cultures and religions will expect the person to be cared for in the family circle, and this can put immense pressure on the primary carer. This is particularly acute where the person with dementia and the primary carer come from different cultures.

### **Q4**

#### **ANSWER:**

As the person's dementia progresses, they may regress further and further into their early memories, and this is very difficult for a person not familiar with this background. Professional carers, day care workers, etc need to be prepared to

enter into this world, and respect cultural traditions, while also respecting the rights of the carer.

**Question**

**5**

**ANSWER:**

In my opinion, both lines of research must be followed. Understanding of the disease and interactions is essential for the care of people with dementia and the welfare of carers. Research into treatment and hopefully prevention or cure is essential given the projected demographic for the disease

**Q6**

**ANSWER:**

I think a diagnosis should be made as early as possible, and treatment started immediately. The only risk I can see is that it is not easy to tell at an early stage what form of dementia it is. The diagnosis might be wrong, and many people are diagnosed with Alzheimer's when they are in fact suffering from another form of dementia, but medication is easily withdrawn if it proves unsuitable, and I believe everyone should have a chance. My husband was diagnosed as Alzheimer's, and was prescribed anticholinesterase medication. Four years later the diagnosis was changed to Primary Progressive Aphasia, but he continued to receive the medication, as it suited him well though it would not have been prescribed had the original diagnosis been correct. Whether or not the diagnosis should be conveyed to the individual should be at the discretion of the primary carer. Some people might be upset by the label, and 'memory problems' would suffice as a diagnosis. Others would be more upset by not knowing what is wrong with them. Only the person who knows them best should decide.

**Q7**

**ANSWER:**

In my experience, people become more excluded as the disease progresses, largely because of difficulties in communication. Different groups would perceive dementia differently. For example, church groups would hopefully try to be supportive. Former work colleagues may find it hard to accept the changes, and adapt to the changing relationship. Hobbies become difficult. Friends may continue to invite the person to a round of golf, for example, but as the disease progresses and ability and behaviour deteriorate, the invitations stop coming. It's important to keep trying for as long as possible, as regular contact will help people to understand. I don't think it's a problem of stigma, so much as a lack of understanding of how to treat the person. There needs to be much more education, not just of people who deal with dementia regularly, but of people like police, firemen, bank tellers, people who will probably come into contact with someone with dementia from time to time.

**Q8**

**ANSWER:**

I think stigma may deter some people from seeking help in the first place, particularly if they suspect what the diagnosis will be. I'm not aware of any problems with accepting treatment, but there is considerable reluctance on the part of the person to accept the need for professional carers, or day care. They can be seen as baby sitters, and regarded as demeaning.

**Q9****ANSWER:**

Yes, I do think so, but the degree of involvement must depend on the person with dementia. He may find it difficult to follow conversations in larger groups, and may feel he is being ignored. But he should be included for as long as he is comfortable with the situation. It comes down to education again. It also puts the onus on the primary carer to maintain contacts. Unfortunately, people are not going to seek you out!

**Q10****ANSWER:**

I think it is helpful. Every person is different, and only by knowing their background, their personality and the problems they have faced can anyone hope to understand the changes dementia brings. Pain is difficult to identify where there is no communication, and knowing the person well and observing body language is the only way to tell. Challenging behaviour is often the result of undiagnosed pain, or may be a character trait that the person has always had. I believe anti-psychotics should only be prescribed when everything else has failed.

**Q11****ANSWER:**

In my experience, there has been no change in personality. My husband is still the person I married, his personality hasn't changed at all. Thankfully, I've had an easier journey than many. Identity is a different issue. A person may be defined by his job and his place in society. These will change as dementia progresses, and the person may have sense of isolation, and will need support to find a new role.

**Q12****ANSWER:**

Radical changes in mood or behaviour can put an intolerable strain on a marriage, particularly if the person becomes aggressive, and threatens or attacks the spouse. The carer may have to take control of finances, have to become the dominant partner, and this changes the balance of the relationship. It can mean

the end of all plans for retirement, and the carer can feel he/she has been robbed. Where an offspring is caring for a parent, the relationship also changes, and the son/daughter has to look after the parent. This can lead to resentment on both sides. The carer might find it difficult to juggle the needs of the parent, their career, and their own relationship and family. They may feel that their life is on hold.

### **Q15**

#### **ANSWER:**

I think there will inevitably be difference. In the later stages of dementia, other problems are likely to intervene. Infections, such as pneumonia or mrsa, failure of swallowing mechanism, stroke, neck of femur fractures. Should a PEG be fitted when the swallow mechanism fails? Should the heart be restarted if it stops? Should pneumonia be treated? C.Diff? The failure of swallow may indicate the breaking down of bodily functions. Fractures often follow a loss of balance and mobility. Repeated infections may also indicate failure of function. The doctor has then to determine if treatment will cure the problem, what quality of life will remain if the problem is resolved, and what the person himself would want. The feelings of the primary carer must also be taken into account. My own feeling is that if there is no longer any quality of life there should be no intervention. But as long as there is any enjoyment of life, every effort should be made to prolong it. A diagnosis of dementia should not in itself be a reason not to treat.

### **Q13**

#### **ANSWER:**

I think every effort should be made to balance them. For example, in the EMI unit my husband is in, every effort is made to dress residents as they would have dressed, and keep their hair in their familiar style, even though most of them are no longer aware of this. The problem arises when the person is not at this stage, but is still living independently. It's very difficult to impose cleanliness and tidy dressing if the person refuses. I don't think it would be right to impose.

### **Q14**

#### **ANSWER:**

Very difficult. Every effort should be made to let the person understand the issues. The primary carer would be the best person to do this, and would be able to choose a time when the person is at his/her most lucid. Decisions about best interests become particularly difficult when the decision to be made concerns life-sustaining treatment. A judgment about best interests and the withdrawal or withholding of such treatment involves factors such as the likelihood of treatment being successful and the side effects or burdens the treatment might impose. Some are concerned that this may require a doctor to

make a judgement about the objective value, and not only the subjective quality, of a person's life.

#### **Q16**

##### **ANSWER:**

I believe there should be consultation between the health professional and the welfare attorney. The welfare attorney's views must be taken into account, as the person has granted them that power. In any conflict, the attorney's views should prevail, as the person's would had they had the capability. I have had experience of this. Our GP decided to stop treating my husband's infections, because they were recurrent. I have welfare POA, (Scottish law), but was not consulted, or even directly informed. My husband has no communication, so his wishes could not be known. I wrote and expressed my views to the practice manager, and the decision was overturned. In my view, it was completely unethical for the GP to make this decision without consultation.

#### **Q17**

##### **ANSWER:**

I think they are an excellent idea, particularly for someone with dementia. They are likely to know when they have had enough, but may be unable to communicate it. It's very hard for the family to make decisions like DNR, or don't treat infections, and family members can disagree. If they have the person's wishes in writing, this should be enough. If there is no AD, the family has to decide based on what the person would have wanted if they were able to express themselves. Not easy! However in the case of dementia, the advance directive has to be made while the person is legally competent, and this might be difficult to achieve. In the example of Mrs A above, I would go for option 3, and try to resolve the dilemma by consultation with the attorney. If this could not be achieved, I think the statement has to be followed.

#### **Q18**

##### **ANSWER:**

#### **Q19**

##### **ANSWER:**

In my opinion, yes. For example, if the person is constantly asking for a spouse who has died, or for mother or father, I don't believe it is kind to keep reminding them that the person has died, I'd just say something like 'They're not here just now'. Obviously they would need to be told, and might even attend a funeral of a loved one, but not to be told over and over again. Similarly, if the person is frightened by the term dementia, or Alzheimer's, I'd simply tell them they have memory problems. I don't think a lie is justified just because it's easier, but if it

were to avoid adding to the person's distress, I'd lie.

## **Q20**

### **ANSWER:**

When it comes to driving, the well-being of other road users has to be taken into account. As soon as there is any possibility of risk, the person should be stopped from driving. Going for walks alone is a grey area. We should allow as much freedom as possible, but once the person starts falling, they really need to have someone with them. The same in the kitchen. As long as they are capable, they should be allowed to cook for themselves. But areas of risk should be minimised, and if at all possible there should be supervision. Microwaves and electric kettles should be used instead of cookers, provided the person is capable of using them. Safety is the only criterion.

## **Q21**

### **ANSWER:**

Only as a very last resort, when the safety of others is at stake. People should not be restrained just to make life easier. The problem arises when the person is a 'wanderer', but when the balance goes he falls repeatedly. He is no danger to anyone else, but is constantly hitting his head as he falls. When he has recovered, he immediately starts wandering again. I would consider restraint justified in case 1 above, but certainly not in the others.

## **Q22**

### **ANSWER:**

I would think certainly for those working in residential care. It would be difficult to provide that education for those caring at home, though carers attending Alzheimer's Society or Alzheimer Scotland support groups could be given guidance there. Talking point provides excellent guidance because people are dealing with a variety of circumstances, and have a variety of viewpoints. A consensus of the views usually presents a balanced picture.

## **Q23**

### **ANSWER:**

For me it comes down to safety again. If smart homes mean that people can safely remain in their own home for longer, then that can only be good. But it must not mean that people don't have personal visits, electronics can never replace human contact. And the carers have to be trained to recognise when electronics are no longer enough. I'm also in favour of tagging. When my husband was out walking on his own, it would have been easier for me if I had known where he was. But every attempt should be made to explain to the person why the tag is being used.

## **Q24**

### **ANSWER:**

I believe the government has a duty to fund care, as we have all contributed all our lives on the assumption that we would be cared for 'from cradle to grave'. Dementia is a disease like any other, and should not be discriminated against. I have nothing against private care homes, provided they are well run, and properly regulated. It's all too easy to neglect people with dementia, they may not be in a position to complain. There have to be regular inspections, and the regulatory authority has to take real note of complaints from families, and be able to act on them.

## **Q25**

### **ANSWER:**

There has to be adequate and suitable provision of respite carers, dementia-specific day care, and respite breaks. Without these the carer's health will suffer. Doctors should be aware of this, and should monitor the health of the carer as well as that of the person with dementia. The person with dementia may resist any form of respite, but the health of the carer is a priority. Every carer should have a care manager, and a contact person that they can call on in case of emergency. This person should have access to the full case notes, and be able to send in an emergence team to help out. If the carer knew that this safety net was in place, he/she would have more confidence in their ability to carry on. The promise 'never to put me in a home' should be reassessed at intervals, and may need to be converted to 'always make sure I am well cared for'. It's a difficult conversion to make, but in most cases will eventually become necessary.

## **Q26**

### **ANSWER:**

The healthcare professional has a duty to the carer as well as to the person with dementia. The health of both must be monitored, and the professional has to step in when there are concerns about the carer. Without imposing decisions, the professional can make strong recommendations to the carer, and thereby remove some of the guilt at having to make the decision.

## **Q27**

### **ANSWER:**

I believe this should apply in all circumstances. The wellbeing of the carer is paramount to the wellbeing of the person with dementia. Wherever possible married couples should be treated as a unit, and if both are frail, they should if at all possible be admitted to a care home together, and kept together for as long as possible.

**Q28**

**ANSWER:**

I haven't had a problem with this. Our GP asked my husband at an early stage if he minded him talking to me. But I think it's easier when a spouse is concerned. It would be more difficult for a son or daughter to get information about a parent, and perhaps a parent would be reluctant to allow offspring to talk about him. I believe we all have a right to privacy, but where that right inhibits appropriate care, the GP should have the right to override it

**Q29**

**ANSWER:**

In my opinion, research should first and foremost be directed at finding the causes of dementia, and finding a cure that would stop it in the very early stages, or even a vaccine against it. Caring is important, but the best care in the world will not make this disease easy to live with. My second priority would be education. The general public needs to be made aware of the horrors of the disease, and the projected number of sufferers over the next 20 years. They need to know that it is not just a disease of old age, that more and more young people are suffering from it. And it needs to be impressed on politicians that it could be them!

**Q30**

**ANSWER:**

I don't think it is right to involve anyone in research without their informed consent. My guiding principle would be 'First do no harm'. If safety had not been established, then drugs should only be given with informed consent.

**Q31**

**ANSWER:**

I would not like to see any relaxation of requirements

**Q32**

**ANSWER:**

For me, the biggest issue of all is end of life care. With most other illnesses, the brain remains intact, and provided they are physically capable of taking the lethal dose, people can make the decision that they have had enough. With dementia, it's different. Anyone who wants to 'opt out' has to make that decision at an early stage, while there may still be reasonable quality of life, and that makes it a very difficult decision. The temptation is always 'one more year', 'our daughter's wedding', until it's too late. So the doctor and welfare attorney have to decide whether to treat and prolong life, to treat and prolong death, or not to treat and let nature take its course. My own feeling is that if there is no

longer any quality of life there should be no intervention. But as long as there is any enjoyment of life, every effort should be made to prolong it, provided there is no advance directive. The other major issue is the NICE recommendation that anticholinesterase medication should not be prescribed until the mmse score drops to 20. This to me is completely unethical. The medication is there, it is safe, and it is effective in a majority of cases. It can preserve quality of life for a number of years. What are the ethical grounds for refusing it to people who may be helped by it?