

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.

## **QUESTIONS ANSWERED:**

### **Question 1**

#### **ANSWER:**

In the early stages it is difficult for everyone concerned to acknowledge the diagnosis. Later on it is hard to accept that our life together (over 50 years in our case) will never be the same again.

### **Question 2**

#### **ANSWER:**

Is it right to keep the doors locked to prevent wandering? A necessity or a convenience? I still ask myself that even though my husband has died. Is it right to pack the case for a period of respite, in secret and smuggle it in into the car to avoid a scene or distress? Is it right to send him to daycare when he clearly would prefer to be at home? When does what should be his care become respite for me?

### **Question 3**

#### **ANSWER:**

Most people of what ever group do not understand what dementia is. They think it's just a memory problem. Without specific dementia training for everyone involved in the care of the elderly in hospitals, care homes and in the community, the care of people with dementia will not be what is required.

### **Question 5**

#### **ANSWER:**

### **Question 6**

#### **ANSWER:**

A diagnosis of dementia is hard to take by all concerned. Surely it is better to defer a diagnosis until such times as symptoms other than those of MIC are displayed. Personally, I expected the diagnosis of dementia in my husband's case, but he didn't. Nor was he particularly upset by it. Perhaps we had waited about the right length of time before seeing the psychiatrist.

### **Question 7**

#### **ANSWER:**

Society needs to be educated in what dementia is. We need to promote the fact that dementia can hit people of all social classes and backgrounds. Leaflets in GP surgeries, libraries eg. to explain what dementia is and that it can affect us all at any time. It is nothing to be ashamed of.

### **Question 8**

#### **ANSWER:**

In my experience stigma is ignorance of what dementia is and it is this ignorance which affects the care.

### **Question 9**

#### **ANSWER:**

Yes. We carried on for some time with all the things we had been involved with prior to the diagnosis. As it became clear that a particular thing was causing us or others difficulty then that particular thing had to be discontinued. But with good support I would say keep doing what can be done for as long as possible. Again, education is the key.

### **Question 11**

#### **ANSWER:**

A person's identity does not change through dementia. That person is the same person but one who has dementia. The personality changes, devastatingly in some cases, but not the identity. Identity is who we are, not what we are.

### **Question 16**

#### **ANSWER:**

The closest relatives jointly should be involved in the decision making even if they are not the welfare attorneys. In more significant cases the final decision should be by the medical professionals providing they can justify their decision for reasons other than age, state of mind or finances. Someone has to decide on healthcare issues but by leaving it to welfare attorneys their decisions could be based on convenience. By the same token, by leaving them to the professionals their decisions could be influenced by factors such as bed-shortages and value for money.

### **Question 17**

#### **ANSWER:**

In an ideal world we would all have made a will and made provisions for our old age and executed Power of Attorney deeds. We would also have made a living

will. But we don't live in an ideal world and the living will could have been manipulated. So generally speaking I would doubt that the advance directive has a part to play in decision making in dementia cases.

#### **Question 18**

##### **ANSWER:**

Some types of Mental Incapacity can be temporary or episodal. Dementia is neither temporary nor episodal - once it's here it's here to stay. The effects of following the guidance in these Acts could be an obstacle in the care and support of dementia patients.

#### **Question 19**

##### **ANSWER:**

A person with dementia who knows they have dementia has a right to a truthful response. A person who has dementia but has forgotten they have it, in my experience, can usually be distracted by talking about some aspect of whatever issue they've raised. For instance, if an eighty-five year old asks where their mother or father is, then ask him or her the parent's name, then the occupation. This is evading a direct answer whether truthful or not but it seems to me to be the kindest approach.

#### **Question 20**

##### **ANSWER:**

In carehomes (I have no experience of care at home other than that given by myself) it is frustrating to hear carers urging their charges to sit down as they'll fall. Couldn't they instead offer an arm of support or let the person manage and be on hand to help if they did fall? This I am convinced is why so many people with dementia 'forget' how to walk. They may be instinctively getting up from the chair through pain in their limbs which is reduced on standing. Freedom of action could be balanced against risk by having more trained carers. This will not happen until a carers role is financially improved thus attracting suitably dedicated staff.

#### **Question 21**

##### **ANSWER:**

I have personally seen how people with dementia are restrained in care homes. I feel the incidents I witnessed were more for the benefit and safety of the staff than for the welfare of that and other residents. In this respect the law is helping the carers. Restraining could be minimised by proper dementia training.

#### **Question 23**

##### **ANSWER:**

If the new technologies are for the benefit of the person with dementia and bring a degree of peace of mind to the carer then that's good or is it? It is fine for a light to automatically come on to illuminate the way to the bathroom but its what happens next there is no technology for. Mopping up, cleaning up. These tecnologies are intended as aids to, and not substitutes for, caring. I had a sensing device which alerted me when my husband, in the next room, made a move to get out of bed . He got up frequently in the night ostensibly for the toilet, invariably he 'went' as soon as he was out of bed, not even making a move towards the toilet. The device was good then. Not entirely. It had an ear-piercing bleep which when cancelled reset itself after two minutes so the least movement within its 'eye' set it off again. The only way round it was to unplug it until I had got him back into bed and then reconnect it and wait for the next summons. If I ran with the speed of an olympian, unplugged the thing and got a bucket into position quickly enough I waS lucky but too wide awake to get back to sleep! Why oh why don't these inventors seek information from those who know, ie the carers who have learned the hard way, and then their technologies would be used more often.! I think that the tagging devices are more associated with criminals and so may not be welcomed by all.

#### **Question 24**

##### **ANSWER:**

The state owes towards people with dementia and their families equality in respect of care and financial support. A person with a physical illness is automatically cared for under the NHS free of charge regardless of that person's financial status. no financial assessment is undertaken. A person with dementia is said to require only social care so if this cannot be provided by his family, social services will conduct a means test and if the criteria fit some financial assistance may be given. Is it morally/ethically right to say that dementia is not an illness in the true sense of the word?

#### **Question 25**

##### **ANSWER:**

As a sole 24 hour carer I was continually told to take care of myself. I'd be no good to my husband if I became ill. As dementia progressed to an advanced stage everyday acts of social care become more difficult. Caring became more physical through his inability to co-operate. Sleep was practically non-existent. Even the most dedicated and willing family carer gets worn out. At that stage I gave in and arranged for a care home. I have felt guilty ever since even though I had been advised by the professionals to take that course of actiion six months earlier.

#### **Question 28**

##### **ANSWER:**

I have been fortunate in that I have always had the informatiion I needed by

asking for it. If I have ever felt that an explanation or answer fell short I always said so. A professional caregiver should be able to pick up from the family carers whether it would be less distressing to withhold some details or whether to give all the facts anyway. I'd say, as a rule of thumb, if the family carers are not asking questions it is because they'd rather not know the answers.

### **Question 29**

#### **ANSWER:**

Research into Alzheimers and other dementias has been going on for years. Technology is advancing continually we're told. Whilst I accept that research into dementia and its causes needs to be continue, there should be a balance between what is spent on that and what needs to be spent on treating and caring for those thousands who have it