

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.

#### **Question 1**

##### **ANSWER:**

The greatest impact on both the lives of people with dementia and those who care for them are often related to fear and the loss of control and dignity. A gradual loss with an understanding is often more frightening for the sufferer who still retains insight, while complete loss is more challenging for families and those who care, as well as for society

#### **Question 2**

##### **ANSWER:**

The ethical issues may often surround the ideas of freedom and control. How to prevent someone wandering, balancing loss of freedom with ensuring safety. As dementia can affect people differently and with varying degrees of speed it is often difficult to establish specific rules.

#### **Question 4**

##### **ANSWER:**

Respecting and understanding ethical questions in a multicultural context requires clear patterns of communications and training particularly where staff and sufferers reflect differing backgrounds and experiences.

#### **Question 3**

##### **ANSWER:**

The different cultural and ethnic understandings may involve attitudes to behaviour, but also need to ensure that the cultural norms of the person are respected at a time when they are not able to act in a way in they would wish.

#### **Question 5**

##### **ANSWER:**

Care and treatment demand different things. We would have concerns about future treatment based on drugs developed from unethical practices. There is small prospect of a 'cure' in the foreseeable future, so treatment would be confined to alleviating symptoms. The increase in numbers of those with dementia will necessitate greater demands for care, and need for specialist training and the delivery of high quality and competent care.

#### **Question 6**

##### **ANSWER:**

As with many major illnesses and has been seen in cancer care, patients respond differently to news. Some wish to know and be told everything others do not. Given the difficulties in diagnosing dementia, and the unknown pattern of progression, there needs to be great care in how early diagnosis is treated and to ensure that individuals are informed sensitively, by qualified professionals and that the probable consequences and implications are carefully and fully explained. Knowing that the inevitable is to happen, long beforehand, can lead to greater fear, stigma and anxiety, but may allow for more thoughtful planning.

### **Question 7**

#### **ANSWER:**

Society perceives dementia with fear. Fear of loss of control and fear of humiliation. Current debates on stem cell research have added to the underlying perception that the stigma particularly of mental ill health, is too great to live with. The onset of dementia seems to be perceived as depriving a person of their humanity and therefore of a place in society. We certainly need to promote a much clearer understanding of dementia, its various forms and how to respond to it. People will now talk about cancer quite openly, the same needs to be achieved for dementia.

### **Question 8**

#### **ANSWER:**

The stigma associated with dementia is great. It is almost an acknowledgment of defeat. Because the illness can be protracted and because the essence of the person is often perceived to change, it is greatly feared.

### **Question 9**

#### **ANSWER:**

While a person is able to be supported and offers no harm to themselves or others by being in a community with which they are familiar, it would help both the greater understanding of dementia, and those who wish to remain independent for as long as possible, if they are supported in the community. This will only work when there is excellent community support, such options are not the cheap options. Real care in the community, which values and supports the person is expensive.

### **Question 10**

#### **ANSWER:**

Person centred care starts from trying to understand as much as possible about the person, in order to ensure that the package of care given respects their personality, values, desires and wishes, as well as their physical, medical and emotional needs. If correctly applied and not merely used in a formulaic sense,

then it is helpful

**Question 11**

**ANSWER:**

This will vary from person to person and may depend on the severity and length of the illness.

**Question 12**

**ANSWER:**

One of the difficulties for carers and families is in retaining their image or reality of someone they have known for many years and not letting their love of the person be clouded by the consequences of the illness. The reality of living with the illness may make huge demands on families which they may not be able to fulfill, and which engenders a sense of guilt or failure.

**Question 13**

**ANSWER:**

This will often depend on how well those involved with the person knew them before their illness. Many of these decisions also involve medical treatment decisions. It is important to respect the values a person has always held. It is also important to ensure that a person is not deprived of treatment, because their quality of life is not seen to be as good as it was.

**Question 14**

**ANSWER:**

Again, this depends on the consequences of the decision. If a person is only just lacking in capacity, they may still be able to understand some of the process. There is a tension in deciding on best interest, and in ensuring that the interests of the person lacking capacity are adequately voiced and respected.

**Question 15**

**ANSWER:**

The fact of dementia should not preclude the giving of life saving treatment.

**Question 20**

**ANSWER:**

It is a difficult tightrope to walk, balancing risk. Considering risks covers such a broad spectrum, and each case is different in relation to what may be seen as a risk. Freedom of action and avoidance of harm need constant reassessment.

**Question 21**

**ANSWER:**

The use of restraint should be limited.

**Question 22****ANSWER:**

Yes.

**Question 23****ANSWER:**

This may often depend on motivation. Just as drugs may be abused to keep the elderly sedated, so electronic constraints may be used to control people and reduce staff costs. If they are used to enable and to encourage independence they would be beneficial.

**Question 24****ANSWER:**

People with dementia may need to be treated as individual members of our society and respected as human beings. The state cannot abandon those with dementia, nor does it abandon those with physical ill health. What is still unclear is the framework in which we can provide high quality care for those suffering dementia, and respecting the differences and their differing needs in the end of life context.

**Question 25****ANSWER:**

The needs of the person with dementia may not be able to be met by the family - the needs of the family must then be addressed.

**Question 26****ANSWER:**

The professional needs to assess the level of care which is provided and whether there are alternatives which would be more appropriate.

**Question 27****ANSWER:**

Where the main carer is a spouse who may also have care needs the best interests of both parties need to be considered.

**Question 28**

**ANSWER:**

Currently, too little information is often given.

**Question 29**

**ANSWER:**

In the immediate short term, the effect of research should be to enable the provision of the most appropriate care.

**Question 30**

**ANSWER:**

those lacking capacity should not be involved in any research which is harmful or causes them any distress.