

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:**

**Q5**

**ANSWER:**

Research such as the 'FITS' project seems important with staff training and creating a supportive regime. Research on antipsychotics/neuroleptics or other medications also seems important for those who might still need restraint. Ongoing work into plaques/tangles seems to be bringing further insights.

**Q6**

**ANSWER:**

Diagnosis as early as possible. People will be aware of 'something wrong'. Explanation seems to come as a relief. Not knowing what is happening can cause more anxiety and even depression.

**Q7**

**ANSWER:**

Media publicity of late has raised awareness but like death dementia is a taboo word for many. Publicity is the major way and should work as we have found with cancer over the years. At present many people see dementia=forgetting and are largely unaware of the general cognitive decline.

**Q9**

**ANSWER:**

Yes but the experience needs to begin at the very beginning of onset. The support of relatives is very important. New affiliations are not always appropriate. Visiting a cafe for morning coffee/afternoon tea can be stimulating.

**Q10**

**ANSWER:**

Yes the concept as explained by Kitwood and further developed by Prof. Brooker ,David Sheard et al is highly significant and is being used successfully in training courses. It should not be abandoned because it has become somewhat debased by over use and often to mean no more than 'good'. The concept crucially defines the human being: we see the person with all normal human attributes

before we see the dementia.

## **Q11**

### **ANSWER:**

Certain traits become exaggerated with dementia but there remains something fundamental about the very being of a person to the end.

## **Q12**

### **ANSWER:**

It can destroy relationships and cause arguments in families especially where responsibility falls on only some members of the family. Sometimes it can have the opposite effect and result in greater bonding eg with a man/wife. Sometimes previous wishes might have to be modified in the interests of sufferer and carer eg re going into a nursing home.

## **Q19**

### **ANSWER:**

It can permissible and best practice depending on relationship of patient/carer.  
Question: Is it in the best interests of the patient?

## **Q21**

### **ANSWER:**

At home, carer (husband) should decide in consultation with GP. 'Any form' seems too wide. Every attempt must be made to avoid hurting the person. The criterion must always be: ascertain what is in the interests of all parties involved.

## **Q22**

### **ANSWER:**

'Education' seems a bit formal. General guidance is given, it seems, successfully in Alzheimer's Cafes, support groups and drop-in centres

## **Q27**

### **ANSWER:**

This broader focus should be made as soon as a person has been identified as having dementia.

## **Q29**

### **ANSWER:**

Research is needed in three areas: cause, cure, care. The basis for funding

should be the quality and the relevance of the research for improving the condition of sufferers and/or their carers. The quality of the institution for research is also a consideration. The A/S QRD consumer programme seems an excellent model for selection of appropriate research.

### **Q30**

#### **ANSWER:**

Depends on the research. If the research involves observation only I see no problem. An example is the SOFI mapping of nursing home residents as part of inspections. Relatives are contacted normally and I have yet to find any problem over this.

### **Q32**

#### **ANSWER:**

I consider 'occupation' of people with dementia an ethical matter and not simply a psychological one. Every one has the right to companionship developed through a one to one relationship. 'Activity' time can be valuable but it is different and more difficult to personalise. The CSCI June report is one of the latest to record lack of interaction outside the functional matters of eating/drinking etc. The most telling comment on all this comes from the verses left by an old woman ('Crabby old woman')in a dementia ward. She had been ignored and misunderstood by staff.