

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 29

ANSWER:

With the complex nature of the disease, research into dementia can be broken down into: prevention, diagnosis and treatment (whether mild/moderate/severe).
Prevention: This will come from initiatives in promoting better public health as has been seen by other diseases such as cancer and diabetes. In fact epidemiology studies have already indicated this, as has also the recent findings that the 'vaccine' approach for Alzheimer's disease may not be beneficial.
Diagnosis: Due to past and current research, there has been a great improvement in our ability to diagnosis (by use of both psychological testing and new imaging technology) not only dementia in general but also the specific forms of dementia. The future here will be co-coordinating the approaches that are being developed in order that a standard methodology is created. Biomarker studies and genetic susceptibility studies are currently being actively studied. However, with respect to the former, initial studies have not been encouraging and the end increase or decrease in genetic susceptibility may be small, if indeed new genes are found. However, this approach has been an important area to study and as yet may provide clues to the development of the disease. With respect to Biomarkers these may come more form physiological biomarkers rather than biochemical due to the ability to detect these in the living brain, and this approach will possibly come from the new imaging technology mentioned above.
Treatments This is the area of research with most significance. We still have a fundamentally poor understanding of what occurs in the aging brain and specifically one that is suffering from dementia. We need research to investigate this, as this will illuminate potential drug targets. Treatments will inevitable focus on the mild to moderate levels of dementia, as the damage that has occurred in the later stages will probably always be irreversible. Two specific areas that should be focused on involve the loss of synaptic and metabolic function of cells ie there is loss of the connections between nerve cells and there is also the death of neurons.

Question 30

ANSWER:

I would envisage that most members of the general public would feel that mild interventions could be possible but anything above taking urine or blood samples would probably be unacceptable. However, even with these 'non-invasive' procedures a member of the family should be present/informed that this might occur. Indeed more invasive procedure eg removal of tissue would not be possible because of the necessary compliance of the subject. Therefore guidelines of what samples could be taken are necessary. In actual fact one of the major problems concerns the obtaining of what are considered normal controls ie

it is the relatively healthy people who do not donate their brains.

Question 31

ANSWER:

In the last few years the increase in 'form filling' and 'red tape' has been notable. Obviously ethical guidance is necessary but there does appear to be excessive forms especially as either the material is already deposited in eg brain banks or involves non-invasive samples such as urine samples. This has resulted in either the slowing of progress or the putting off of researchers to develop new models. The latter is particular important as recent statements from the MRC have highlighted the apparent lack of suitable models of human diseases including dementia.