

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.

## 1. GENETIC ASPECTS OF DEMENTIA

Questions: Should patients be tested for genetic conditions? And when should they be told the results? Should close relatives be tested?

A number of mutations (genetic biochemical errors) may be associated with certain types of dementia. These are not common, but are more likely to be found among the younger patients, especially where there is a clear family history. Huntington's disease is a well-known example and mutations can be found among patients with Alzheimer's disease, frontotemporal dementia and other disorders of this type.

A definite family history with evidence of dominant transmission of dementia should indicate a possible mutation, though even in this situation one cannot be certain that one would actually be found. So a person with a family history is not necessarily at risk, though fear and anxiety about this must often be present. An accurate family history is not always available if, for instance, the parents had died early of unrelated conditions.

Let us suppose that a definite mutation has actually been identified in a patient with dementia. In theory, the test could then be offered to close relatives, which effectively means sibs or children, who then have the unenviable choice of whether to take up the offer. They are faced with following alternatives:

1. To refuse the offer: the answer then remains unknown, with probable anxiety on that account.

2. To take up the offer:

If the result is POSITIVE : the subject may be faced with anxiety or depression and may have to make important life decisions.

If NEGATIVE: the subject is likely to feel much relieved, but may possibly feel guilt at having escaped, while other close relatives are affected.

3. The decision could be deferred, perhaps until considering marriage or starting a family. Antenatal tests, such as pre-implantation genetic diagnosis, are a possible option.

Obviously such tests should not even be considered unless a suitable counselling service is in place.

It may be argued that tests should only be performed if there were some definite treatment (or preventive measure) available to an individual with a positive test. While in many instances there may be no possible action at present, in 10 - 20 years perhaps, the position may well be different.

Schott, Fox and Rossor suggested ( J Neurol Neurosurg Psychiat 2002): 'The possibility of a familial form of dementia should be considered in all patients presenting with dementia at a young age'. ('Young' in this context usually means less than 65 years of age).

#### Public information

There is nowadays a lot of public information, but not always well understood by the general public. Erroneous and sensational health information can appear in the press, but the ethical aspects of irresponsible journalism are possibly not within the remit of the Nuffield Council.

#### Insurance and genetic testing

##### Concordat between Government and Association of British Insurers (ABI)

There is now a Moratorium on the use of genetic test results by insurance companies until the year 2011. This does not apply to life policies for over £500,000 nor to certain other expensive policies.

The Moratorium means that genetic test results can only be used by insurance companies when authorised by the Government Genetics and Insurance Committee (GAIC). The only currently authorised genetic test is for Huntington's Disease and then only where the application is for life insurance.

Possibly other similar genetic disorders might be added to the list in the future.

Otherwise companies cannot enquire about or enforce a genetic test and customers who have taken a predictive genetic test can obtain life insurance cover without disclosing the result. On the other hand, customers may disclose a negative genetic test if they wish, which should override a positive family history.

#### Questions:

1. Why has Huntington's disease been picked out to be excluded from the Moratorium?
2. Are we prepared to allow other genetic disorders to be excluded when the Moratorium runs out in 2011?

## 2. EARLY ONSET DEMENTIA

Question: Should there be greater provision for younger people with dementia?

In the past, responsibility for this group of patients (under 65 years of age) was poorly defined, with the result that many of them fell through the safety net which should have been provided by the health and social care services. In the

UK at present, there are about 18,000 cases in the 30-64 age group, with 20% (3600 cases) aged between 30 and 50.

To focus attention on this matter, a joint working group from the Royal College of Psychiatrists and the Alzheimer's Society was set up and recommended improvements in services such as support groups for patients and carers, day centres, residential and nursing homes, respite care, information, advocacy and counselling. (As might have been expected, many of the younger patients prefer not to attend the day care and other facilities set up mainly for the elderly and clearly need an organisation more appropriate to their own age group).

The main recommendations are:

#### Named consultant

A named consultant should be designated to take charge of the clinical service, bearing in mind the high level of functional and behavioural problems which occur in young persons with dementia. The consultant is likely to be an old age psychiatrist experienced in the management of dementia and its associated problems.

#### Neurology services

An early referral to neurology services for diagnostic tests and neuroimaging is of crucial importance. This should lead to earlier and more accurate diagnosis, the starting of specific treatment and referral to other appropriate services.

#### Genetic factors

Genetic factors may be particularly important in this group of patients who may have disorders such as Huntington's disease or other familial causes of dementia. Easy access to specific genetic tests and counselling is essential.

#### Minority ethnic groups

The prevalence of dementia in these groups is not exactly known. Language and cultural differences may create extra problems. Special efforts should be made to engage with these patients.

#### Substance misuse

Drug and alcohol misuse are associated with dementia in about 10% of cases. Strong efforts should be made to identify such patients as dementia may be treatable and possibly preventable.

For details see: Royal College of Psychiatrists web site

A report by the Royal College of Psychiatrists and the Alzheimer's Society (March 2006)

### 3. DIAGNOSIS

Question: When should a diagnosis of dementia be made?

Early diagnosis of dementia is clearly desirable, but an erroneous diagnosis may be a disaster bearing in mind the dread of this disorder held in the community.

In my view the definitive diagnosis should be made only by a Consultant Neurologist (ideally one with a special interest in dementia), after appropriate scans, psychometric tests etc have been done.

The clinical diagnosis, moreover, is quite often overturned at autopsy. Brain donation should be encouraged and the Consultant should discuss the results of this in full with the patient's family, who are often concerned about hereditary disease.

### 4. RESEARCH

Question: Should patients with limited mental capacity be involved in research?

Large sums of money from both government and charity go into research on the causes of dementia. One main purpose is the development of drugs and other therapy to prevent, alleviate or even cure the disorder. Much of the point would be lost if promising drugs could not be tested in patients with limited mental capacity and it could even be regarded as unethical to rule out this possibility. Suitable ethical procedures must be devised.

### 5. CARERS

Question: Do carers receive enough help and advice?

Most patients with dementia will eventually need 24 hour care. If cared for at home the burden is likely to fall primarily on the spouse or partner.

Dementia may strike at almost any age. Younger adults have usually been in full time work, may have a spouse or partner of similar age and possibly a young family. The partners of older patients may themselves not be in good health. Home carers may well become exhausted, short of sleep and bad-tempered resulting in feelings of guilt which may be carried far into the future. They often lack professional support in this area.

Many will have to give up much activity outside the home in order to look after the patient themselves or will have to find enough money from work or savings to pay for professional carers. Few can afford this and available benefits usually

fall far short of covering the costs of care. Carers may have difficulty in finding out about such benefits. It is now the duty of the Local Authority to inform carers about all benefits to which they might be entitled.

SOURCES of information which should be made available to all carers.

Age Concern

Alzheimer's Society

Benefits and Health Information Service