

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.

Dr Guy Brown

### Question 32

#### **ANSWER:**

The key term of reference of the Council was: "to identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern". However, while the Council does an excellent job on many issues, the consultation paper fails to identify a major ethical issue. Perhaps the Council thinks this issue is too controversial or political to be usefully addressed, but if so its absence here constitutes a failure of nerve by the Council, and a failure to fulfil its terms of reference. The growing prevalence of dementia is in part a result of past and present priorities in medical research, public health and the common culture. Therefore those priorities are in part to blame for the current situation, and if we want to change that situation then we need to change our priorities. The overwhelming cause of the increasing prevalence of dementia is increased longevity. Life expectancy at birth has increased linearly at 2 years per decade since 1840 in the UK, while prevalence of dementia increases exponentially with age. The clash between the linear and exponential is producing an explosion in dementia. The consultation paper downplays that explosion: but a recent, extensive MRC survey has shown that the prevalence of dementia is 30% in the year before death in the UK. Increased longevity has come about because we have prioritised length of life over quality of life. These priorities are illustrated in the data quoted on page 35: 40% of medical research papers (on long-term conditions) are on cancer and cardiovascular disease (i.e. the main causes of death), whereas 1.4% are on dementia (i.e. the main contributor to years lived with disease in the elderly). Is this ethical? By 2050, unless we change our priorities, 50% of us, or rather our children, will be dying with dementia. Is this ethical? I believe the right thing to do is to fund medical research in proportion to the contribution of a disease to years lived with disability and disease, not in proportion to its contribution to death. The latter approach, and the overwhelming emphasis of biological and medical research to extend life, has helped generate the current problem. Only by addressing this huge issue can we hope to stem the coming explosion in dementia. The Council may not want to address this issue, but if it follows its terms of reference, it can not ignore it. A separate but related issue is that of euthanasia and assisted suicide. This is a key concern of the public. Is it really too big an ethical issue for the Council to even mention?