

BIOETHICS AND DEMENTIA: A CHALLENGE FOR SCIENCE



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Chairing the Nuffield Council on Bioethics, a position which I was honoured to take up in January 2008 for five years, is an exciting and unique opportunity for someone like me who works on social values and public policy.

It allows me to debate cutting-edge issues in science and medicine, and to do so with some of the most interesting (and pleasant) people in the UK. Eminent lawyers, scientists, clinicians, journalists and philosophers are brought together. After a thorough process of consultation and deliberation, the Council publishes reports that aim to clarify bioethical issues and influence the development of policy.

THE ETHICS OF DEMENTIA

Most recently, the Council considered the ethical dilemmas raised by dementia. An expert Working Party, ably led by Tony

Hope, Professor of Medical Ethics at Oxford, spent almost two years considering the difficult dilemmas that people with dementia, their carers and healthcare professionals have to face on a day-to-day basis. These include:

- deciding when and how to communicate a diagnosis;
- balancing a person's safety with their need for independence and freedom;
- deciding what is in the best interests of the person with dementia, for example when making decisions about their care and treatment;
- recognising that the needs of the person with dementia may sometimes conflict with the needs of others, especially carers;
- tackling discrimination against people with dementia; and
- deciding what priority to give to dementia research.

The Working Party published its report *Dementia: ethical issues* in October 2009. It found that there are many ways in which we can work together as a society to help people with dementia, and their carers, have a better quality of life.

RESEARCH PRIORITIES

One important conclusion was that the amount of funding available for dementia research appears low, given both the number of people with dementia and the effect dementia has on people's lives. Research funding bodies rightly choose to fund research that is important and high quality.

However, these criteria alone are not enough to make sure that there is a fair distribution of research funding between the needs of very different parts of the population. We concluded that the major research funders should explain more clearly how and why they divide their research funds between areas of research that have the capacity to benefit very different groups of the population. If necessary, they should take active steps to support and encourage researchers to carry out high-quality research in dementia. More research into the experience of living with dementia and how people with dementia can be supported to live the best possible lives is particularly needed.

RESEARCH PARTICIPATION

People with dementia who understand what is involved in a particular research project decide for themselves whether or not to take part. Those who cannot decide for themselves may be able to take part as long as a number of legal requirements are met. We concluded that more should be done to make it easier for those who have expressed a wish to take part in research to do so. For example, clinical trial networks, which bring together doctors and people with dementia who want to take part in research, should be encouraged; and the possibility of giving welfare attorneys the power to decide if a person with dementia should take part in research should be considered. At present, this is possible in

Scotland but not in England or Wales. The Council will be discussing these findings with the major funders of research and others in the coming weeks.

THE FUTURE OF DEMENTIA CARE

The report ties in with current policy discussions. A Green Paper *'Shaping the Future of Care Together'*, published in July, sets out long-term reform proposals on how we as a society provide care for older people. To help them prepare for future debate around adult care, Parliamentarians and other policy makers are invited to discuss the issues raised by caring for people with dementia at the Council's annual 'Bioethics in Parliament' event in the Houses of Parliament. The event, to be held on 10th November 2009, is supported by Evan Harris MP, Brian Iddon MP, Earl Howe and Lord Harries of Pentregarth, and will entail presentations and debate, followed by a drinks reception. For more information contact Catherine Joynson at cjoynson@nuffieldbioethics.org.

Over the next two years the Council will be considering the rise of genetic testing and online medicine; the implications of advances in biofuels; and the donation and use of bodily material such as gametes, blood, tissue and organs in medical treatment and research. At a time when the biosciences present us all with challenges and opportunities, all those on the Council hope that their work will be of public benefit and advance the public understanding of bioethics.