

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 Nori Graham

**Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?**

Please can I refer you to the work of Professor Martin Prince at the Institute of Psychiatry carried out over the last 10 years with the 10/66 research group affiliated to Alzheimer's Disease International. They have looked at these issues throughout the world.

Many references eg 10/66 dementia research group. Care arrangements for people with dementia in developing countries. *International Journal of Geriatric Psychiatry*, 2004, 19: 170-177

**Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?**

As per last response

**Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?**

Attempts at early diagnosis are likely to be unreliable and may give rise to unjustified anxieties. Cognitive abilities in everyday life vary between individuals for example a bank manager and a person doing a very routine job. So diagnosis should be timely in relation to the circumstances of the individual.

**Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?**

I have been involved with the fight against stigma for many years. There has been real change but it is still the case that the word 'Alzheimer's' remains dreaded. I strongly believe that the availability of high quality services reduce stigma.

#### **Person-centred care and personal identity**

**Q10 Is the idea of *person-centred care* helpful, and if so, in what way?**

If focus on the individual with the disease has to be called person centred care then it has to be a good thing!

**Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?**

I do not think that dementia changes identity. You remain the person you were when you were born. The more you can learn about the person, their life and their previous personality the more you will be able to understand the person and support them better.

### **Making decisions**

**Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?**

Essential

**Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?**

The state has a duty that the health and social needs of the population are met at a reasonable level. Individuals relinquish their rights to spend all their income in exchange for an expectation that the tax they pay will ensure they receive decent health and social care when they need it.