

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 John Kelly

QUESTIONS ANSWERED:

Q1 ANSWER: Both the psychological and practical aspects of dementia have the greatest impacts on the lives of people with dementia, their families, and their carers. For society there is the increasing economic burden of providing adequate care and support for those affected. Psychological deterioration for the individual with dementia puts them on a path to inevitably increasing dependence on the state for care and support. Concomitantly, families and carers (often elderly themselves) are increasingly implicitly expected to care for their loved one at home. This increases the risk of negative impact on the carers mental and physical health, and thus an increasing expressed need for access to a safety net of state respite care. A broad range of expert support is required, not merely an army of well intentioned support workers, but rather a proper multidisciplinary, co-ordinated support and treatment structure that is responsive to the needs of dementia sufferers and their families. Families and carers are likely to manage longer without hospitalization when this sort of structure exists. A service structure that is sufficiently flexible to take a holistic approach to care. Dealing with the evolving needs of the dementia sufferer, providing psychotherapeutic support to sufferers and carers where required, adequate health care and medical support, occupational therapy, speech therapy, etc. The most important part of this structure and most frequently cited as a 'must have' by carers locally is the availability of adequate respite care. Individually, Dementia sufferers often ask 'what can I do to help my memory' whilst carers (paid and otherwise) most frequently ask 'What can I do to help or how should I respond to a particular verbal utterance or behaviour'. There needs then to be some form of consistent practical advice available on these issues, preferably delivered in an open honest and face to face discussion by someone able to talk competently and with authority about memory strategies and help finding solutions to difficult to comprehend/manage verbal and behavioural manifestations. The proposed dementia care advisor (contained in the consultation on dementia care document) might help facilitate this.

Q2 ANSWER: One of the most frequent ethical problems I personally encounter is linked to the psychometric assessment of people with dementia. Issues related to assessing the capacity to participate in giving informed consent to such assessment, when such an assessment may ultimately yield results which have negative