

26 October 2011

Committee Assistant  
Health Committee  
Committee Office  
House of Commons  
7 Millbank  
London SW1P 3JA

Dear Sir / Madam

### **Inquiry on social care**


I am writing on behalf of the Nuffield Council on Bioethics, an independent body that examines and reports on ethical issues in biology and medicine. This response is based on the findings of a two-year inquiry carried out by the Council between 2007 and 2009 on the ethical issues raised by dementia. This response therefore focuses on the social care implications for people with dementia.

Paragraph numbers in brackets refer to the Council's report, which can be downloaded in full at: [www.nuffieldbioethics.org/dementia](http://www.nuffieldbioethics.org/dementia)

A copy will also be posted to you, along with a hard copy of this response.

Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely



Hugh Whittall  
Director

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Professor Albert Weale FBA

**Deputy Chairman**  
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## Background

- 1 Following a two-year inquiry, the Nuffield Council on Bioethics published the report *Dementia: ethical issues* in October 2009.<sup>1</sup> The Working Party that produced the report was chaired by Professor Tony Hope of Oxford University, and included members with expertise in medicine, nursing, neuroscience, law, sociology and philosophy, and members representing people with dementia and carers. To inform its deliberations, the Working Party held a public consultation and spoke to people with direct experience of living with dementia and those working in the field. This response highlights the report's recommendations which are relevant to the Select Committee's inquiry on social care.

## Accessing services

- 2 We welcome the wide-ranging debate that is currently taking place around personal budgets, which aim to give people more choice and flexibility over their care. However, after a diagnosis of dementia, people will still need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services which people with dementia and their families may potentially use. Such support may take many forms, but we suggest that a key element will be the identification of a single individual to liaise with the person with dementia and their family, and with whom a trusting relationship can develop. **We welcome the proposal in the English dementia strategy to pilot possible models of 'dementia care advisers', whose role would be to help people diagnosed with dementia access appropriate services and support. We suggest that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible** (paragraph 3.27).
- 3 People with dementia experience a number of disadvantages in the current system, especially in the way services are subdivided into 'social' and 'health' services, and indeed they may sometimes get 'lost' between the two systems. Their needs are largely classed as 'social', despite the fact that the direct cause of their highly complex symptoms is progressive damage to the brain, and all the evidence suggests that much more skilled care than is currently generally on offer would significantly enhance the quality of people's lives and promote independent living. Under the current system, this means that support services may only be made available when a crisis has already been reached because of the pressure on social services departments to prioritise those in greatest need. Moreover, the level of 'hidden' dementia, particularly among those living in care homes, means that even where people are in touch with social care systems, their particular needs arising out of their dementia may not be recognised. **The access of people with dementia to the services they need should not be determined by classifications of care. In allocating resources, and in determining standards of care, it should make no difference whether the intervention is classified as 'health' or 'social'**. If the intervention addresses a problem that arises as a result of the disorder then the level of priority given to providing that

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<sup>1</sup> Nuffield Council on Bioethics. *Dementia: ethical issues*. London: Nuffield Council on Bioethics. Available at: [www.nuffieldbioethics.org/dementia](http://www.nuffieldbioethics.org/dementia)

intervention should be based on the needs of the person and the benefits and the costs of the intervention and not on which service provides it. Any future proposals relating to adult social care services must take this point fully into account, despite the current difficult economic climate (paragraph 4.39-4.41).

### **Respecting individual needs**

- 4 We stress the importance, if care is to be of appropriately high ethical standards, of support that promotes the autonomy and well-being of the person with dementia and that recognises their individuality and value as a person. The National Institute for Health and Clinical Excellence has made a number of recommendations in these areas, emphasising the importance of promoting independence and helping maintain a person's skills, responding flexibly to fluctuating abilities, providing care in a stable and familiar environment, and enabling the person to participate in activities which they enjoy. The English dementia strategy similarly stresses the importance of community personal support services "ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of broader family circumstances." The strategy further highlights the role of housing and housing support services in supporting people with dementia to live in their own homes for as long as possible, and the importance of ensuring people are able to 'live well' with dementia in care homes. **We very much welcome the increasing emphasis on services which are flexible and appropriate to the individual and which enable them to live well with dementia – an approach based on respect for the needs, preferences and personhood of the individual person with dementia (paragraphs 3.30-3.31).**

### **The 'small' things**

- 5 The responses we received from our various consultative activities suggest that the 'small' things – the 'micro' aspects of life and their effects – are of considerable significance both to autonomy and well-being. Quality of care and ethical issues are at least as much to do with the everyday as they are with the 'big' questions around the end of life. **How things are done, so that people with dementia feel valued individuals, will often be far more important than the particular structure or format of services.** These 'micro' aspects of care are often primarily a question of *attitude*, of professionals and care workers genuinely believing that the person with dementia for whom they are providing care matters as an individual, and is a 'person' in the fullest sense of the word. Such attitudes emerge in such mundane, everyday circumstances as whether a care worker in a residential setting checks whether the person with dementia would like sugar in their tea, or encourages them to express preferences in the clothes they put on in the morning (paragraph 3.5).

### **Care partnerships**

- 6 Carers will often know the person with dementia better than anyone else, and hence are likely to be well placed to advise on their particular support needs. However, they do not necessarily know about the nature or progression of dementia, nor what care interventions are possible. Support is therefore

needed from professionals who do possess such knowledge. Conversely, health and social care professionals will be familiar with care planning, care provision and caregiving, but unfamiliar, at least initially, with the personal history, preferences and values of the person with dementia. **It is therefore crucial that professionals and carers work together in genuine partnership, in order to ensure that people with dementia benefit from their joint expertise and joint knowledge.** Such a 'care partnership' should be founded on a basis of mutual respect for the different forms of knowledge of the different parties, and on the premise that all concerned are seeking to help the person live as well with their dementia as possible. It is important to ensure that where formal services are available, they should be offered on a flexible basis, matched to the actual needs and wishes of those receiving them and to the support that carers are able and willing to offer (paragraph 7.20-7.21).

### **Financial and social support for carers**

- 7 Caring for a person with dementia is expensive. Costs incurred by carers include factors such as lost earnings, paying for respite and other care, and investing in adaptations and assistive technologies for the individual for whom they are caring. The financial impact on the household may be even more dramatic in cases of early-onset dementia where the person with dementia is the primary breadwinner in the household at the time of diagnosis. A carer's needs for support are not limited to financial matters, but also encompass emotional and practical support. Some carers find it very difficult to ask for the help that they need in order to cope with the situation in which they find themselves, especially where their adult identity has been based on a solid foundation of competence, capability and independence. Our emphasis on solidarity highlights society's responsibility to support people with dementia and their carers. **This responsibility extends to informing carers, openly and systematically, of the social and financial support to which they are entitled: support should not only be available to those who know enough about the system and have sufficient persistence to assert their rights.** We again commend the proposed role of a dementia care adviser or similar (see above) who should be well placed to ensure that carers of people with dementia are better informed about their entitlements. A timely diagnosis is also important for carers, given that without such a diagnosis carers will experience significant difficulty in obtaining the help and support they themselves need (paragraph 7.27-7.30).
- 8 It is also essential that carers are supported in considering their *own* interests, as well as those for whom they care. However, it may be very difficult for a carer genuinely to consider their own interests alongside those of the person for whom they care, even if they know that this is what the person with dementia would have wished. **Professionals such as doctors, nurses, clinical psychologists and social workers have an important role to play in supporting carers explicitly to consider their own needs and interests when weighing up difficult decisions, particularly around future care options** (paragraphs 7.35-7.37).

## **Dementia: an ethical framework**

- 9 These recommendations are based upon a 6-part 'ethical framework' set out in the Council's report. As with any framework, it will need to be applied flexibly, and with compassion. There will rarely be one 'right' answer to any particular ethical difficulty.

**Component 1: A 'case-based' approach to ethical decisions:** Ethical decisions can be approached in a three-stage process: identifying the relevant facts; interpreting and applying appropriate ethical values to those facts; and comparing the situation with other similar situations to find ethically relevant similarities or differences.

**Component 2: A belief about the nature of dementia:** Dementia arises as a result of a brain disorder, and is harmful to the individual.

**Component 3: A belief about quality of life with dementia:** With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

**Component 4: The importance of promoting the interests both of the person with dementia and of those who care for them:** People with dementia have interests, both in their autonomy and their well-being. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values. Autonomy is not simply to be equated with the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning. The separate interests of carers must be recognised and promoted.

**Component 5: The requirement to act in accordance with solidarity:** The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole.

**Component 6: Recognising personhood, identity and value:** The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions (para 2.4 and box 2.1).