

1st October 2009

Dr David Harrison
Clerk of Health Committee
7 Millbank
London SW1P 3JA

Dear David

**House of Commons Health Select Committee call for evidence:
The future of social care services**

I am pleased to attach a response from the Nuffield Council on Bioethics to the above call for evidence.

We focus in the response on relevant findings from the Council's report *Dementia: ethical issues*, published on 1st October 2009, a copy of which has been enclosed with this letter. The report can be downloaded at: www.nuffieldbioethics.org/dementia

The report was prepared by a Working Party established in November 2007 to examine the ethical issues raised by dementia. To inform its deliberations, the Council held a public consultation and spoke to people with direct experience of living with dementia and those working in the field. Although our conclusions are made in the context dementia, we believe these to be relevant to a more general discussion on adult social care.

I hope that this is a helpful contribution to the inquiry. Please let us know if we can be of further assistance.

Yours sincerely



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Extracts from *Dementia: ethical issues* Executive Summary

Some general points about the care of people with dementia

9. We emphasise two particular points which we believe to be especially important in dementia care. First, we argue that **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** (paragraph 3.5). Secondly, we highlight the enormous importance of families and friends in the care of many people with dementia. It is our view that an attitude of working with families and other carers, supporting them in their own care of the person with dementia, is most conducive to the interests of the person with dementia and best recognises the centrality of relationships with family and friends for many people with dementia. **We suggest that the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown within the family** (paragraph 3.12). Such a partnership would involve a relationship of trust between professionals and carers, based on mutual respect for each other's role and expertise.

Information, communication and signposting to services

13. There is ample evidence that, in many cases, people are presented with a diagnosis of dementia and simply told to come back in a year's time. **It was argued forcefully in one of our fact-finding meetings with people in front-line dementia care that such a lack of information and support in the immediate aftermath of diagnosis is simply morally wrong. We agree** (paragraph 3.26). Access to supportive care, including appropriate information, emotional support, and a variety of forms of practical support, is essential for people to live well with dementia, making the most of all their retained abilities.

14. People also need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services that people with dementia and their families may potentially use. We suggest that an important 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).

Ongoing care and support

15. **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** (paragraph 3.31). A commitment to making services as flexible and responsive as possible does not necessarily entail spending more money; rather, it involves listening to the needs and wishes of the person for whom the service is being provided and adjusting the support on offer in order to help them in what they value most.

16. The ‘small things’ of care are particularly important in ensuring that care is genuinely supportive of the individual, and enhances that person’s autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.

The role of society in providing care and support

21. People with dementia experience a number of disadvantages in the current care system, especially in the way services are divided into ‘social’ and ‘health’ services. Many of their needs, for example for help with personal care, are classed as ‘social’, despite the fact that the direct cause of their symptoms is progressive damage to the brain. 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.

22. We argue in Chapter 2 that dementia is a medical disorder and that the needs arising out of the disorder should therefore be met in the same way as those arising out of other serious illnesses such as cancer. It is not acceptable to make people with cancer wait until their support needs have reached a crisis before providing that support and nor should it be regarded as acceptable for people with dementia to wait in this way. **The essential ethical point to be made is that 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’** (paragraph 4.41).

Financial and social support

56. Caring for a person with dementia is expensive, encompassing 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. Emotional and practical support is also crucial.

57. 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, who should be well placed to ensure that carers of people with dementia are better informed about their entitlements. We reiterate that 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 7.30).

Ethical dilemmas in care

41. As we emphasise in the introduction to our ethical framework, ethical dilemmas arise on a daily basis for all those providing care for people with dementia. Such dilemmas may arise in mundane situations, but they are problematic and stressful, and those providing care often feel isolated and unsupported in responding to them. Yet the way in which they are handled may have a significant effect on the quality of life of both the person with dementia and others surrounding them. Moreover, the problems arising in dementia are complex: there is rarely one over-arching value or consideration that can be used to solve them, and hence judgment has to be applied in the light of every particular case. In view of this, our general conclusions are as follows:

1. Specific guidelines, rules and laws have a particular but limited role to play: they may help to set a framework pointing to ways in which problems may be resolved but they can rarely provide a definitive answer to a specific dilemma. Any such guidelines will need to be interpreted in a flexible and compassionate way when applied to a specific situation, with a focus both on the interests of the individual with dementia and on the interests of others directly concerned.

2. Professionals are in a position to support both carers and care workers, in addition to facing ethical problems themselves. They should have access to ongoing education to help them in both these roles. Education in ethical decision making, however, should not be limited to those with 'professional' roles: care workers are required to respond to ethical problems as part of their daily work, and should have

access to the ongoing education needed to equip them to respond appropriately.

3. All those involved in direct care – carers, care workers, health and social care professionals, and volunteers – should have access to forums for sharing and receiving support in making ethical decisions. Carers and volunteers who wish to access more formal courses in ethical decision making should be able to do so (paragraph 6.3).

Recommendation 9: We recommend that the UK Departments of Health consider, as part of their dementia strategies and workforce planning, how all those involved in direct care of people with dementia can access appropriate education and support in ethical decision making. (Paragraph 6.3)

Joint support for the person with dementia and their carer

51. Our ethical framework emphasises the importance of giving close attention to the autonomy and well-being of carers, both for the benefit of the person with dementia and because carers matter in their own right. We also argue that autonomy should be seen in 'relational' terms: that is, that a person's sense of self and self-expression should be seen as being firmly grounded in their social and family networks. In addition, most people would wish that their carer's interests should be given considerable weight: their interests include their carer's interests. When autonomy is understood in these terms, then in order to support a person's autonomous wishes and values it will be necessary to support the whole family and social structure.

52. A diagnosis of possible dementia has implications that extend well beyond the individual receiving the diagnosis. Close family and friends, and especially the partner of the person with dementia, have to adjust to the ramifications for their own lives and come to terms with a shared future which may be very different from what they had all envisaged. **An important implication both of our emphasis on solidarity and of our 'relational' approach to autonomy is to emphasise that professional support should have a wide focus that includes helping the family to support the person with dementia, rather than being limited to an exclusive and direct focus on the person with dementia (paragraph 7.19).**

Trust in carers

53. The issue of trust is central in any caring relationship. Most carers provide a level of care that compromises their own health and well-being, and are concerned to help and support the person with dementia as much as they are able. Given this trust-based relationship between the person with dementia and their carer(s), we suggest that **unless there is evidence to the contrary, there should be a presumption of trust in carers by health and social**

care professionals and care workers. Such trust is a key part of any 'caring partnership', and without such trust it is highly unlikely that the person with dementia can be given the best possible support (paragraph 7.23).

Considering carers' interests

58. Carers need support in considering their own interests, as well as those for whom they care. When making a decision for a person who lacks capacity, others are legally required to act in that person's best interests. At first sight, this suggests that the interests of the person with dementia should always be placed above those surrounding them. Yet interests are often complex and intertwined. In a family, it will rarely be the case that a single person's interests always take priority: rather some consideration will be given to everyone's interests and some degree of compromise found. **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 (paragraph 7.37).**