

26 March 2012

Delivering Dignity Consultation
NHS Confederation,
29 Bressenden Place,
London SW1E 5DD

Dear Sir / Madam

Commission on Improving Dignity in Care: consultation on draft report and recommendations

I am pleased to enclose a response to the above consultation from the Nuffield Council on Bioethics, an independent body that examines and reports on ethical issues in biology and medicine.

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

Yours sincerely



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Response from the Nuffield Council on Bioethics to the Commission on Improving Dignity in Care: consultation on draft report and recommendations

Introduction

- 1 In October 2009, the Council published a report, *Dementia: ethical issues*,¹ which presents an ethical framework that aims to address problems that arise in connection with dementia care, together with recommendations for policy makers. The report was the result of a two-year independent inquiry led by Professor Tony Hope, a consultant psychiatrist and professor of medical ethics from the University of Oxford.
- 2 To inform its recommendations, the Working Party consulted a wide range of people, and received 200 responses to its open consultation. Importantly, large numbers of families and friends of people with dementia wrote to the Council expressing their experiences and views, which became an invaluable resource when drafting the report. In response to the open consultation, research, and fact-finding meetings with people who work in dementia care, the Council's report focused on how people with dementia might be further helped to 'live well' with the condition.

Support of the Commission's draft recommendations

- 3 Based on its conclusions in *Dementia: ethical issues*, the Nuffield Council supports several of the Commission's recommendations, predominantly in regard to care homes.
- 4 Firstly, we endorse the Commission's focus on engaging with older people, and enabling them to fully participate in shaping their daily lives. In its report, the Nuffield Council concluded that it is important that people with dementia feel that they are valued individuals (paragraphs 2.48-2.53, and 3.5). The Council therefore supports the Commission's draft recommendation that "care homes need to work with residents to create an environment that make their lives happy, varied, stimulating, fulfilling and dignified. This means involving older people as full and active participants in shaping their daily lives, rather than seeing them as passive recipients of care."
- 5 Moreover, the Nuffield Council concluded that an "emphasis on solidarity highlights society's responsibility to support people with dementia and their carers" (paragraph 7.30). In light of this responsibility, we support the Commission's draft recommendation that "building links with the wider community is an important part of creating a caring environment and developing a culture of openness."
- 6 The Nuffield Council also noted the importance of end-of-life care, and the need for strategies to develop end-of-life care models which are specific to

¹ Nuffield Council on Bioethics (2009) *Dementia: ethical issues*, available at: <http://nuffieldbioethics.org/dementia>.

people with dementia (paragraph 3.45). It therefore accepts the broad draft recommendation of the Commission that “providing end-of-life care tailored to the wishes and needs of each individual is central to dignified care in all care homes.” Furthermore, we would like to highlight the concept of ‘advance care planning’, which is an important part of palliative and end of life care (paragraphs 3.45-3.47 and 5.47-5.49). This tool aims to encourage all people who are approaching the end of their lives to discuss and document their wishes about their future care. Wishes set out in an advance care plan may include the refusal of particular forms of treatment in particular circumstances. However, they may also include wishes about where the person would prefer to be as they are dying; the people they would most want to have around them; whom they would wish to be consulted about their care; and other aspects of their lives that they find most important and that may help make the end of their life as peaceful and supported as possible.

- 7 In addition, the Nuffield Council recommended that “the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown with the family” (paragraph 3.12). It therefore supports the following draft recommendation from the Commission: “Families, friends and carers should be seen as partners in care, where the older person wishes it, not as a nuisance or interference. They are the people who were there before and will be there after formal care services have gone, and are a vital emotional link.” The Nuffield Council also supports the Commission’s draft recommendation that families, friends and carers “should be encouraged to be an active part of the care home’s community.”
- 8 Our report also welcomed 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 (paragraph 3.27). Therefore, the Nuffield Council supports the spirit of the Commission’s recommendation on dementia care in hospital settings: “With around a quarter of people in hospital having dementia, national clinical director for Dementia Professor Alistair Burns has argued that 10 per cent of staff should be dementia experts, 50 per cent dementia trained and 100 per cent dementia aware. We recommend all hospitals use this benchmark.”
- 9 The Nuffield Council concluded that “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” was to be welcomed (paragraph 3.31). The Council therefore supports the Commission’s draft recommendation on the importance of care plans: “It is important that care recognises what the person would like to do for themselves. Homes should ensure that every resident has a care plan that refers to residents’ personal wishes, preferences and priorities and to the support they need in order to retain and develop their sense of dignity and personal identity.”

- 10 Finally, regarding the draft recommendation that “boards and managers have a duty to ensure buildings are fit for use for older people, particularly those with dementia”, the Nuffield Council would like to highlight good practice guidance on building ‘dementia-friendly’ environments published by organisations such as the Dementia Services Development Centre in Stirling,² and the Oxford Centre for Sustainable Development.³ The Nuffield Council also draws attention to its own recommendation that “the Equality and Human Rights Commission should give particular consideration to the discrimination currently experienced by people with dementia, and take appropriate action to publicise both the legal duties to which all ‘service providers’ are subject under the Disability Discrimination Act 1995 to ensure equal access to their services by people with dementia, and appropriate ways in which this could be achieved. In addition, the Disability Discrimination Act 1995 Code of Practice should explicitly address dementia with examples of good practice” (paragraph 4.31).

² See, for example, Dementia Service Development Centre, University of Stirling (2007) *Best Practice in Design for People with Dementia* (Stirling: DSDC); Health Facilities Scotland and Dementia Service Development Centre, University of Stirling (2007) *Dementia Design Checklist* (Glasgow: Health Facilities Scotland), available at: www.hfs.scot.nhs.uk/publications/dementia-checklist-v1.pdf. See also the Iris Murdoch building at Stirling University which itself is an example of dementia-friendly design. More information available at: www.dementia.stir.ac.uk/about.

³ Oxford Centre for Sustainable Development and Housing Corporation (2004) *Neighbourhoods for Life* (Oxford: Oxford Brookes University), available at: www.brookes.ac.uk/schools/be/oisd/sue/wise/resources/Neighbourhoods%20for%20Life%20Checklist.pdf.