

14 November 2012

The Nursing, Midwifery and Care-Giving Vision Team
c/o NHS Commissioning Board
Quarry House
Quarry Hill
Leeds
LS2 9UE

Dear Sir / Madam

Developing the culture of compassionate care: creating a new vision for nurses, midwives and care-givers

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. We welcome this consultation and, in particular, its focus on the aim of developing a culture of compassionate care.

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: consultation on developing the culture of compassionate care: creating a new vision for nurses, midwives and care-givers

Introduction

In 2009, the Nuffield Council on Bioethics published a report entitled *Dementia: ethical issues* (available at <http://www.nuffieldbioethics.org/dementia>). The Council's report to this consultation draws on the recommendations and conclusions of the report. In particular, it will highlight key themes which are explored by the consultation document, especially those in relation to dementia care.

Training and support for carers

At several points in the consultation document, the importance of training and supporting professional carers is raised. For example, on page 16 of the consultation document, support training initiative for health and care staff working with people with dementia is highlighted as an 'area of action' and, on page 17 the importance of understanding and responding to the needs of carers is similarly highlighted.

The Nuffield Council agrees that the training and support for carers must be a key aim for the development of dementia care. But it is important to recognise that there are many circumstances in which care is given by family members, or by other informal, unpaid carers, and training should be available to both professional and unpaid carers. As we note in paragraphs 7.27-7.30 of our report, it is also important for carers to have easy access to support, including financial, emotional and social support. We highlight two examples from practice of schemes that provide support and education for carers (Box 7.2).

We would also like to highlight an aspect of our report which has not been overtly acknowledged by the consultation document, namely the importance of support for carers in making ethical decisions. Specifically, at paragraph 6.3 of our report, we recommended that all those involved in direct care should have access to forums for sharing and receiving support in making ethical decisions. This is in light of our conclusion that healthcare professionals have an important role to play in supporting carers explicitly to consider their own needs and interests, especially when 'weighing' difficult decisions in relation to the person for whom they care.

Adapting methods of communications

At paragraph 2.12 of the consultation document, it is noted that, as a result of consultative activities, it was mentioned that there is a "need to adapt communication styles to meet differences presented by age, disability or language and to embrace new forms of communication through the use of technology". The importance of communication was similarly highlighted in our report at paragraph 3.28, which states that a key aspect of recognising and relating to the person with dementia is to find appropriate forms of communication through which they may be reached, however advanced their dementia may have become.

With regard to communication in the context of people with dementia being enabled to take part in research we noted in paragraph 8.45 that the ability of people with dementia to give, or withhold, valid consent to research should not be underestimated. The information provided in both written and verbal form, however, may need to be provided in a different form for people with some cognitive impairment compared with people without such impairment.

Maximising well-being

We welcome the consultation's commitment to maximising the well-being of cared-for individuals. Specifically, the consultation notes, at paragraph 3.4, that it is the role of healthcare professionals to "advise people on how to look after their physical and mental health... and to lead to early interventions that improve both current and future individual well-being." Similarly, in paragraphs 2.35-9 of our report, we note that an important component of an ethics framework for dementia is well-being. Specifically, we note that a person with dementia clearly has an interest in being helped to maximise their well-being, and we note that 'well-being' includes 'objective' factors such as maintaining cognitive ability, and also 'moment-to-moment' experiences of happiness or sadness meaning that the opportunity to improve well-being will arise even in very advanced dementia.

Moreover, we also welcome the consultation's conclusion at page 16 that, in order to help people to stay independent, maximising well-being and improving health outcomes, it is necessary to support people to maintain their independence for as long as possible. In endorsing this aim, we draw attention to the importance of autonomy in the context of dementia care (see paragraphs 2.26-34 of our report), as both people with dementia and also their family carers have an interest (in an ethical context) in maintaining their autonomy. We emphasise that autonomy should be understood in a 'relational' sense, not simply in the sense of 'non-interference'. People are not isolated individuals but embedded in a network of relationships – and enabling autonomy in someone with dementia involves fostering those relationships, and providing support to the person with dementia so that they can be encouraged to retain and express their sense of self.

Partners in care

The notion of carers as 'partners in care', and of people with dementia as citizens with their own views and contribution to make, are both key messages of our report and we welcome this approach set out in the consultation document that "the people we care for, and in many respects their families and carers, are our partners in care and our practice must reflect that."

Similar observations are made in our report, at paragraph 7.19 where we emphasise that professional support should have a wider focus that includes helping family and friends to support the person with dementia, rather than being limited to an exclusive and direct focus on the person with dementia and at paragraph 3.31 where we emphasise the importance of flexible services that respond to specific needs and preferences of the individual, rather than a one-size fits all service.