

Response to the draft NICE guidelines on ‘Dementia: assessment, management and support for people living with dementia and their carers’

February 2018

- 1 The Nuffield Council on Bioethics is an independent organisation that examines and reports on ethical issues arising from developments in biological and medical research that concern the public interest. We welcome the opportunity to respond to NICE’s draft guidelines on ‘Dementia: assessment, management and support for people living with dementia and their carers’.
- 2 Our response is drawn from the comments and recommendations of our 2009 report, *Dementia: ethical issues*.¹

Introduction

- 3 The Nuffield Council on Bioethics welcomes the draft NICE guidelines on dementia. We have highlighted specific areas below that are supported by our own findings and recommendations.

Person-centred care

- 4 We welcome NICE’s principles of person-centred care set out in this section. This largely aligns with the components of the ethical framework in our dementia report, particularly components 4 – 6:

- **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 wellbeing. 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.

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

- **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.

1.1 Involving people living with dementia in decisions about their care

- 5 We welcome the recommendations set out in section 1.1.
- 6 While dementia is a harmful disorder, a good quality of life is possible if the person with dementia is seen and respected as a person with values and interests to whom we have the same duties as any other fellow human beings. Amongst the key values underpinning our approach to dementia, should be concern for the autonomy and well-being of the person with dementia, coupled with an attitude of solidarity based on the belief that we are all ‘fellow-travellers’ and dependent, to various degrees at different times in our lives, on each other.
- 7 We recognise that it is not always possible to provide services, or support individuals, in a way which fully respects all these values, because at times they may come into conflict (for example sometimes it may be impossible to promote wellbeing and at the same time maximise autonomy). It is also sometimes necessary to balance the interests of the person with dementia with the interests of carers (see diagram on page 39). However, we emphasised that involving the person with dementia in ‘small’ things or ‘micro’ aspects of their life and their effects is of considerable significance to making the person feel valued and in control.²
- 8 The importance of information, support and access to services immediately after diagnosis was evident in the responses from our public consultation. The needs of any person with dementia and those close to them will vary significantly, depending on individual preference and on the nature and progress of their dementia at the point of diagnosis.³ It isn’t just the access to information, but also the importance of communication itself. 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 the dementia.

Advance care planning

² Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.3 – 3.5.

³ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.25.

- 9 We welcome the emphasis on offering “early and ongoing opportunities” for people to be involved in planning care in the future, including lasting powers of attorney (health and welfare), advance statements about wishes, and advance decisions to refuse treatment.
- 10 Welfare powers of attorney are a very good way of promoting a person’s autonomy interests. Indeed, they have many advantages over an advance decision as they permit decisions to be made in the light of up-to-date knowledge both of the person’s clinical needs and the care options available.⁴

1.3 Care coordination

- 11 We welcome the emphasis on a ‘single named health or social care professional’ responsible for co-ordinating care. In our report, we found that people need help accessing what is inevitably a fragmented support system, given the wide range of services available. We welcomed the use of professionals whose role would be to help people diagnosed with dementia access appropriate services in the UK and suggested that there is a strong ethical justification for these to be introduced throughout the whole of the UK.⁵

1.4 Interventions to promote cognition, independence and wellbeing

- 12 We very much welcome the recommendations set out in this section, particularly the emphasis on the importance of offering “a range of activities to promote wellbeing that are tailored to the person’s preferences.” We welcome the emphasis on services or activities which are flexible and appropriate to the individual.⁶ How things are done, so that people with dementia feel like valued individuals, will often be far more important than the particular structure or format of services.
- 13 If care is to be of appropriately high ethical standard, the support provided needs to promote the autonomy and wellbeing of the person with dementia and recognise their individuality and value as a person.

1.7 Managing non-cognitive symptoms

- 14 We welcome the emphasis on the importance of identifying clinical and environmental causes of agitation; offering psychosocial and environmental interventions to reduce distress; and only offering antipsychotics as a last resort for those who are at risk of harming themselves or others or experience agitation, hallucinations or delusions that are causing them severe distress.

⁴ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 5.55.

⁵ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.27.

⁶ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.31.

- 15 Support such as information and advice, psychological therapies to improve confidence, practical help in the home, and assistive technologies have an important role to play in improving the quality of life and promoting independence for people with dementia.

1.11 Supporting carers

- 16 We welcome the recommendations in this section of the NICE guidelines. It is important that carers are supported financially, emotionally and practically. Service providers have a responsibility to inform carers, openly and systematically, of the social and financial support to which they are entitled.⁷ Carers should also have access to ongoing education to help them respond to ethical problems.⁸

1.13 Staff training

- 17 We welcome the guidance in this section, particularly for all staff to have “training in person-centred care.” Professionals and care workers providing care to people with dementia should also have access to ongoing education to help them respond to ethical problems.⁹

Contact

Hugh Whittall
Director
Nuffield Council on Bioethics
hwhittall@nuffieldbioethics.org

⁷ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 7.30.

⁸ Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 6.3.

⁹ Ibid.