

Nuffield Council on Bioethics

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Dear Sir or Madam

Shaping the Future of Care Together

I am pleased to attach a response from the Nuffield Council on Bioethics to the above consultation.

We focus in the response on relevant findings from the Council's recent report *Dementia: ethical issues* (published in October 2009), which can be downloaded at: www.nuffieldbioethics.org/dementia

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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**NUFFIELD
COUNCIL ON
BIOETHICS**

A response from the Nuffield Council on Bioethics to the UK Government's consultation *Shaping the Future of Care Together*

Introduction

People with dementia, and those who care for them, face difficult ethical dilemmas on a day-to-day basis. The Council established a Working Party to examine the ethical issues raised by dementia in November 2007. The group 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, during which it received 200 responses;
- held a series of 'fact-finding meetings' with people with direct experience of living with dementia and with those working in the field of dementia; and
- held a one-day 'deliberative event' in Birmingham, involving over 50 members of the public with no direct experience of dementia.

Appendix 1 of the report includes more details of the Council's method of working.

The report *Dementia: ethical issues* was published in October 2009. It sets out an ethical framework to help those providing day-to-day care, together with recommendations for policy makers in the following areas:

- promoting autonomy and well-being through an ethical approach to dementia care
- including people with dementia in society
- making decisions about the care and treatment of people with dementia
- dealing with day-to-day ethical dilemmas in care
- recognising the needs of carers
- research funding and participation.

The report, and a summary, can be downloaded at: www.nuffieldbioethics.org/dementia. This response highlights the conclusions and recommendations that are relevant to the consultation questions in *Shaping the Future of Care Together*. Paragraph numbers in brackets refer to paragraph numbers in our report.

Government consultation question 1

We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

- a) Is there anything missing from this approach?
b) How should this work?

Comments

Prevention services

1. We welcome the proposal to give people the right support to help them stay independent and well for as long as possible. **We concluded that people should have access to good quality assessment and support from the time they, or their families, become concerned about symptoms that relate to a possible diagnosis of dementia** (paragraph 3.18). We welcomed the fact that improvements in early intervention and diagnosis are highlighted in the English dementia strategy and Scottish dementia priority paper but cautioned that the timeliness of a diagnosis will depend on the person and family concerned.

A joined-up service

2. We welcome the proposal to give people a joined-up service, where social care, health and housing services, the benefits system and all other forms of support should work more smoothly together.
3. People with dementia currently 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.
4. Dementia is a medical disorder and the needs arising out of the disorder should 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).**

Information and advice

5. 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 agreed (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.
6. Whilst the principle of patient confidentiality is an important one in the doctor-patient relationship, a diagnosis of dementia has important implications not only for the person with dementia, but also for close family members who are likely to take on a significant caring role and need appropriate information and support to do so. **Professionals responsible for communicating a diagnosis of dementia should actively encourage the person with dementia to share this information with their family, making clear that the diagnosis is of importance to those providing informal care and support, as well as to the individual concerned (paragraph 3.23).**
7. We welcome steps to make the care and support system simple and easy to navigate. We concluded that people with dementia need help in accessing the support system, given the wide range of health and social services that they 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 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. We suggested that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible (paragraph 3.27).**
8. Carers should also be informed, 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 commended 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 reiterated 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).

Personalised care and support

9. **We 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.
10. 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.
11. We would welcome a system that recognises the vital role that carers play, and provides appropriate support for them. We highlighted the enormous importance of families and friends in the care of many people with dementia. **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). It was 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 suggested 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.

End of life palliative care

12. The consultation document does not mention end-of-life palliative care. NICE has recommended that a palliative care approach, considering a person’s “physical, psychological, social and spiritual needs”, should be

adopted from diagnosis to death. End of life care for people with dementia is a matter of particular concern, with evidence to suggest that people with dementia are less likely to receive palliative medication, have attention paid to their spiritual needs, or be referred to palliative care specialists than people who do not have dementia. We noted, and welcomed the fact that the English dementia strategy, the Scottish dementia priority paper, and the draft action plan for Wales all identify end of life care for people with dementia as an important target for improvement, and that the various UK end of life strategies similarly recognise the particular needs of people with dementia. **It is clear that a key factor will be the development of models of end of life care which are appropriate to dementia, and we welcome the English dementia strategy's commitment to the development and evaluation of such models.** We also strongly agree with the National Council for Palliative Care that close working locally between those responsible for dementia care and those responsible for end of life care is absolutely crucial (paragraph 3.45).

Government consultation question 2

We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- a) Do you agree?
- b) What would this look like in practice?
- c) What are the barriers to making this happen?

Better quality and innovation

13. We agree that a vital way of improving the quality of services is through the people who deliver the services. Staff must have the right training and skills to provide the care and support that people want.
14. Those providing support and care for people with dementia face ethical problems on a daily basis: for example when balancing safety with freedom; deciding what is in the best interests of the person with dementia; and recognising that the needs of the person with dementia may sometimes conflict with the needs of others who also deserve consideration. While legal frameworks and guidelines are helpful in guiding practice and decision-making, they need interpreting and applying to specific situations, and cannot provide precise answers to particular ethical problems. We proposed an ethical framework (see Box 2.1 in the report) to help those who face these ethical problems, while emphasising that there is rarely a single 'right' answer in any specific situation. We emphasised, however, that guidelines and frameworks alone are not enough to provide proper support for carers, care workers and professionals. **Education and support in ethical decision making, in the form of ongoing professional education, courses and peer**

support, must be available to all those providing care on a paid basis, and to all carers who wish to access such support. We recommended 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)

Obstacles to joined-up working

15. Our belief was that a person with dementia is to be valued in exactly the same way as a person without dementia. We set out in the report the importance of solidarity: of recognising each other as ‘fellow-travellers’ in life, with mutual duties of support and assistance. These values underpin a clear moral imperative to tackle the stigma which is still pervasive in dementia and which leads not only to difficulties and delays in accessing services but also to exclusion, to a greater or lesser degree, from mainstream society. We noted that the English dementia strategy includes as one of its key aims “improving public and professional awareness and understanding of dementia”, and states the intention of carrying out a national campaign to challenge misperceptions, emphasising that “a person with dementia is no less a person because they have dementia.” The Scottish dementia priority paper and the draft action plan for Wales similarly include commitments on public awareness raising and information. We strongly endorsed the emphasis placed on this issue and would go further by urging positive action to be taken under the Disability Discrimination Act to ensure that people with dementia do not suffer discrimination in their access to services. ‘Normalising’ dementia in this way is key to the removal of attitudinal barriers. We also applauded the increasing awareness of the importance of involving people with dementia in developing, and indeed running, services provided by health and social care for their benefit (paragraph 4.29).
16. As mentioned above, **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 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 4.41).
17. A further way in which solidarity can be made real in practice is through the more widespread use of voluntary activity. Organisations such as local Alzheimer’s societies, Age Concern groups and Alzheimer Cafés depend on volunteers to run a range of services, including advocacy, befriending and sitting services, and practical domestic help such as shopping, help in the house and gardening. It is well recognised that there are a number of

factors that may deter, obstruct or delay people who might otherwise volunteer. These include:

- delays with carrying out Criminal Records Bureau checks;
- excessive and inappropriate bureaucracy;
- expenses incurred by volunteers;
- concern by potential volunteers that they would lose entitlement to benefits;
- stereotypes about the age and sex of volunteers;
- risk aversion on the part of organisations that could benefit from volunteers;
- organisations' insurance policies not covering volunteers; and
- antipathy towards the use of volunteers in profit-making companies.

The Commission on the Future of Volunteering has recommended that the Government should set up a working party with stakeholders in order to remove any unnecessary or disproportionate obstacles to volunteering, and we warmly endorsed this proposal (paragraph 4.43-44).

Government consultation question 3

The Government is suggesting three ways in which the National Care Service could be funded in the future:

- Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- Insurance – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

18. We do not wish to make specific recommendations that may have significant economic implications, nor recommendations about the precise balance to be maintained between individual, family and state financial contributions to the cost of care. This is because we are not in a position to consider the 'opportunity costs' of any such recommendation. However, we welcome the fact that such a wide-ranging debate is currently taking place (paragraph 4.38) and we draw attention again to the importance of ensuring that *access* to care is not determined by classifications of care as 'health' or 'social' (paragraph 4.41).