

Nuffield Council on Bioethics

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28 August 2013

FAO: Ms Judith Brooke
Clerk, Committee on the Mental Capacity Act 2005
Committee Office
House of Lords
London
SW1A 0PW

Dear Ms Brooke

I am writing in response to the Select Committee Call for Evidence on the Mental Capacity Act 2005.

Following a two year inquiry, the Nuffield Council on Bioethics published a report in 2009 on the ethical issues raised by dementia, upon which this response is based. The report can be downloaded from: www.nuffieldbioethics.org/dementia.

The report was prepared by a Working Party that was chaired by Professor Tony Hope and included members with expertise in healthcare, law, ethics, psychiatry and neurology.

To inform their discussions, the Working Party held a public consultation and met with representatives from relevant organisations.

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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Director

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MCA consultation response

1. The Nuffield Council on Bioethics welcomes the House of Lords' Select Committee's call for evidence on the Mental Capacity Act 2005. In response, the Nuffield Council would like to draw the Committee's attention to conclusions drawn in its 2009 report *Dementia: ethical issues*. To this end, the Council's response focuses on the MCA in the context of its application to people with dementia. In particular, there are five areas we wish to highlight, four of which are in relation to the Code of Practice which accompanies the Act itself.

Joint decision making for 'borderline' cases

[Re. questions 3 and 12]

2. In cases of dementia, a person's capacity to make decisions will vary; for example, according to the time of day at which they are assessed, or their emotional state when a decision is sought. In such cases, the MCA's Code of Practice is to be endorsed for its approach in highlighting the need to choose the best time and best circumstances for assessing a person's capacity.
3. Despite this, any assessment of a person's capacity is an inexact science, especially in cases where a person has dementia and finds it difficult to communicate clearly. For example, professional opinion may differ as to whether a person does or does not have sufficient understanding to make a particular decision at a certain point in time. In addition, the law takes a binary approach to capacity at present, dictating that a person either does, or does not have, the capacity to make a decision at a particular point in time, and it is difficult to see how else a law could be framed more loosely. This does not, however, mean that this approach to capacity is without issue: for example, in the earlier stages of dementia, very different outcomes may arise from marginal differences in capacity, or indeed in opinions about capacity. We suggest that a way of avoiding these conflicts would be through encouraging the use of joint decision making with trusted family members. This would bridge the gap between the time when a person with dementia is able to make his or her own decisions, and the time when some kind of formal proxy decision making becomes necessary on a regular basis.
4. The use of joint decision making with family members would, of course, depend on heavily on existing family relationships, and levels of trust between the person with dementia and their relatives. However, the ethics framework developed in our report notes that most people do not make autonomous decisions in isolation: rather they come to decisions supported by those close to them and in the light of those relationships. We therefore recommend that the Committee considers amending the MCA's Code of Practice to emphasise the importance of good communication and supportive relationships with families, so that joint decision making is encouraged where appropriate.

Best interests and decision-making: the relevance of past and present wishes

[Re. questions 3 and 6]

5. When considering what kind of decision a person would have made, if they still had capacity, the MCA refers to both 'past' and 'present' wishes and feelings. In many cases, there will be clear continuity between the way people with dementia approach their life now and in the past. However, situations arise where people's past and present views about a particular question or issue will be very different. The MCA's Code of Practice approaches this issue by highlighting the importance of strong views in the past, particularly those set down in writing, but emphasising that these would not be the only factor to take into account when considering best interests. However, we recommend that additional guidance should be provided in the Code of Practice on how past and present wishes and preferences should be taken into account where these appear to conflict. This guidance should emphasise that neither past nor present wishes can automatically take precedence, but that the relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider.

Interpretation of advance refusals

[Re. questions 3, 6 and 11]

6. We are concerned about the current lack of consensus as to whether an advance refusal made under the MCA could be invalidated by inconsistent behaviour after capacity to make the decision in question has been lost. Such a lack of clarity adds to the concerns on the part both of those who wish to write binding refusals and of health professionals who have to act upon them. We therefore recommend that additional guidance should be provided in the Code of Practice on whether advance refusals may be invalidated by inconsistent behaviour after a person with dementia has lost legal capacity to make the decision in question.

Lasting powers of attorney for health and welfare: funding mechanisms

[Re. questions 19 and 20]

7. We recognise that lasting powers of attorney for health and welfare (hereafter 'welfare attorneys') are a very good way of promoting the interests of a person with dementia. For example, they allow decisions to be made in the light of up-to-date knowledge both of the person's clinical needs and the care options available, thus supporting and facilitating decision making on behalf of people who are inherently vulnerable as a result of their declining capacity. To this end, it is our view that welfare attorneys represent a social good. As such, they should, in principle, be available free of charge for everyone. At the very least, a funding mechanism should be found in order to ensure that

when a person is first diagnosed with dementia, they are actively supported in nominating a welfare attorney if they so wish.

The authority of welfare attorneys

[Re. questions 19 and 20]

8. We recognise that although welfare attorneys have the legal authority to make decisions on behalf of the person who lacks capacity, they do not have complete freedom of action, as the MCA obliges them to act in the individual's best interests. While in the vast majority of circumstances the requirement to act in the person's best interests will not be problematic, conflicts may arise in cases where the welfare attorney and health or social care professionals do not agree about the individual's best interests. Indeed, in many of the difficult decisions that arise in dementia, there will be no single 'right' or 'best' answer. It is therefore unsurprising that those involved in making a decision on behalf of the person with dementia do not always agree. In light of this, we recommend that the Code of Practice should explicitly address the question of when it is appropriate for professionals to seek to override the decision of a nominated welfare attorney by approaching the Court of Protection. Both professionals and welfare attorneys would then be clear as to their respective conditions. Our view is that significant weight should be placed on the fact that the person on whose behalf the decision is being taken has actively chosen, in the past, to trust the welfare attorney to act on their behalf. This would suggest that others should seek to intervene only if they have grave concerns about the welfare of the incapacitated person, and not simply because they themselves take a different view of best interests.
9. I attach a copy of the report for the Committee's reference. We are very happy to discuss our recommendations further if required.