

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Professor Bob Woods

Q6 The point at which 'diagnosis' is relevant relates to the availability of treatment and intervention strategies that will make a difference to the person with dementia. At present, there is no justification for diagnosis before the onset of symptoms (indeed, current diagnostic criteria would not allow anything else). The right point for diagnosis currently is when the person or those close to them have concerns about changes. Offering a diagnosis where there are no such concerns makes little sense and even less difference!

Q7 The discourse around dementia is interesting. Peter Whitehouse has drawn attention to the way in which the public image of Alzheimer's, for example, is at odds with what is actually believed by most scientists. The constant media coverage of the latest 'cure' reinforces Alzheimer's as a single brain disease, capable of being beaten, and quite distinct from ageing processes, whereas research tends to indicate there are multiple conditions, for which treatments may well be partial, with no clear dividing line from normal ageing. Attempts to portray the person's experience of 'living with dementia' are encouraging and deserve more attention.

Q10 The idea of person-centred care, as Kitwood intended it, has been tremendously helpful in promoting individuality, the importance of the environment and the value of the person with dementia. Some conceptions of 'person-centred care' have focused on individualisation of care alone, which misses crucial aspects of Kitwood's ideas. There is scope for emphasising more the relationship-centred aspects which were at the heart of Kitwood's theory and the value to be placed on all those who provide care as well as on people with dementia.

Q18 The implementation of the MCA is relatively recent. My observation is that professionals sometimes find it difficult to separate decisions regarding capacity from the person's right to make unwise decisions, and that there is still a tendency to label people as either having or not having capacity, rather than recognising its decision-specific nature. Ultimately, I am sure the MCA will make it easier to support and care for people with dementia, as it provides a clear framework in an area where little guidance was previously available.

Q19 I continue to feel uncomfortable regarding encouraging care workers to lie to people with dementia; even where the initial motivation is the best interests of the person with dementia, too often there is a drift to telling lies for the convenience of the staff. On the other hand, telling the 'whole truth' is rarely appropriate in everyday interactions, dementia or no dementia. Responding to the underlying feelings and emotions being communicated by the person with

dementia is typically a more constructive third way, which allows the care worker to retain integrity, and achieve a deeper level of communication and contact with the person with dementia.

Q20 Most services are now far too risk averse, citing ‘insurance’ and ‘health and safety’ issues as reasons for not engaging people with dementia in a range of activities. The experience of those who have taken people with dementia on ‘adventure holidays’, such as reported by Professor Dawn Brooker, confirms how much is missed in terms of quality of life by an over-cautious approach.

Q21 The use of restraint only to prevent immediate harm to the person with dementia or others seems an entirely appropriate principle. Until this is implemented, it will never be recognised how staff-intensive good quality dementia care must be, and how much investment is actually required.

Q22 Everyday ethics needs to be a regular part of dementia training (and indeed usually is, implicitly, as, for example, person-centred care approaches presuppose a set of values). Recent NICE-SCIE Guidelines recommend expansion of dementia specific training for all involved, and this provides an excellent opportunity to take this forward, as does the Department of Health’s dignity agenda.

Q23 Some of the resistance to ‘tagging’ relates to the comparisons made with the use of tagging with those convicted of an offence, and to the ineffectiveness of the early systems with many people. If a person with dementia wishes to leave a hospital unit, say, then a loud alarm sounding as they exit the door, followed by several staff seeking to block their egress is likely to lead to a confrontation, and possibly an incident of aggression. The more recent emphasis on consent by the person with dementia to tracking devices is welcome, and likely to lead to greater usage. In relation to video-surveillance, care homes are probably the only places in the UK where CCTV does not typically permeate! There is a role for more use of smart technology in care homes and in the community, but often the rate of progress of the person’s condition means that the technology cannot keep pace with the person’s changing needs.

Q25 There is a role for much greater involvement of advocates in dementia care. As the dementia progresses, there is a risk that the best interests of the person with dementia are seen as less important than those of the carer, and advocacy would have an important role in ensuring the perspective of the person with dementia continues to be heard. There is also a need for greater training for professionals in working with family systems and in conflict resolution, so that ways can be found of meeting the needs of both parties, rather than on seeing them as incompatible.

Q27 Although there has been proper attention given to the rights of carers to have an assessment in their own right, there is a risk in seeing person with dementia and carer as two distinct entities – their lives and needs are interwoven and a family systems perspective is needed. More attention needs to be given to enhancing and supporting the quality of the relationship between the person with dementia and their carer; this is a key predictor of quality of life for both parties.

Q28 One of the advantages of early diagnosis is the opportunity to check out with the person with dementia what information can be shared with which family members; in my experience, most are perfectly happy for an open, frank approach. In dementia care, there is much greater openness with carers (rightly or wrongly) than in other mental health contexts, and the need for partnership with family carers is widely recognised.

Q29 There is a need for greater investment in all types of research on dementia – cause, cure and care. Recently, there have been indications that research aimed at improving the quality of life of people with dementia in the short-term is now attracting some funding, after decades of neglect. Whilst cause and cure research is vital, research on care approaches and on the experience of dementia remains an area which requires greater emphasis. Alongside this, greater attention (and funding) must be made available for dissemination and implementation.

Q30 As yet we have little experience of how the Mental Capacity Act will influence research in England and Wales. For the first time, we have a legal framework for involving people with dementia who are unable to give informed consent on their own account in research studies, and certainly for psychosocial research studies the arrangements specified appear to provide appropriate safeguards.

Q31 As stated, it is too early to assess the impact of the MCA on research in England and Wales – so far, no examples of potentially valuable research being prevented have come to my attention.