

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.

Guideposts Trust

What is dementia and how is it experienced?

Q1 In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most by people with dementia and those caring for them?

In our opinion, the greatest impact on the lives of a person with dementia and their carers is the widespread ignorance of the condition across all levels of health and social care organisations. Problems arise because staff do not understand what dementia is and how it impacts on the person and family members. In the absence of understanding and knowledge, care and health staff are unaware of how to help the person and unaware of how their own behaviour can impact on the person with dementia.

The kind of support needed is 'informed' empathic support. Staff should be engaged on the basis that they really care for the vulnerable person and can develop an ability to 'stand in their shoes' and see the world from the person with dementia's viewpoint.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

- Carers being asked for a person with dementia's opinion by proxy
- Assumptions being made about a person with dementia's choice e.g. in a care home with regard to how they might wish to spend time; what they might want to eat/wear; provision or not of spiritual input
- Issues to do with 'restraint' – physical, emotional, chemical, both in the persons' own home and in care homes
- Difficulty of establishing whether or not abuse has taken place, in the person's own home or in a care home
- Not having a 'voice' to participate in decision making, especially at the time when a person with dementia will be 'placed' in care
- Difficulty accessing local information and sources of specialised support. Guideposts Trust developed a local resource to address this issue www.dementiaweb.org.uk which has proved to be hugely

successful with an average of 15,000 hits per year. It is, used by people with dementia, their carers, professionals and members of the public. The model for dementiaweb arose out of the Oxfordshire Dementia Forum's desire to have organisations working together and providing on- line information for people with dementia, their carers and professionals. The Dementia Information Service for Carers (www.disc.org.uk) is a similar online facility now in its fifth year of operation as an advice and information service.

Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

In our experience, the answer to both questions is Yes.

Some groups of people have demonstrated no concept of dementia with no vocabulary to describe the condition. Some groups have expected clinical teams to perform a 'cure', some others have believed that the person with dementia is 'bewitched' and needs to have spiritual cleansing.

Across the professional groups, staff who adopt a medical model of dementia see the illness from a disease/ pathological approach. Staff who adopt a social care model are more likely to see the person first, leading to a person centred approach.

Of course, it is important to know what different groups understand so that care can be tailored around those beliefs and standpoints and hopefully steered towards an approach that benefits the person with dementia.

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Ethical issues in a multi cultural context derive from that culture's interpretation of dementia and means of helping the person with dementia. Different cultural approaches lead to different ways of tackling issues and supporting the person

One way to address this 'differentness' is to first of all understand the differences and perspectives. Then demonstrate methods that are effective or therapeutic or cause least harm.

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

Scientific developments – the most significant development has been the introduction of medications that slow down the progression of symptoms but this has limited application due to prescribing guidance from NICE.

Other developments – nationally, the recent consultation process as part of the Government's national dementia strategy

In-house, Guideposts Trust has developed a Dementia Care Development Pack which aims to improve the quality of care of older people with dementia in care homes. Guideposts Trust also hosts the very successful multiagency collaborative venture of dementiaweb and the advice line DISC

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

From what we understand, the risks are few and outweigh any disadvantage of making an early diagnosis. If a person with dementia and their carers can be given important news, such as a diagnosis, early in the disease, they have time to plan and make decisions which may be denied them later in the journey of dementia.

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Our opinion is that society perceives dementia as a condition which robs people of themselves – that they no longer have any role to play nor do they preserve the right to say what should happen in their life. For example, we have seen families relocate a person with dementia to be nearer to them to meet the needs of the wider family – when the needs of the person with dementia may have been better met by staying in a familiar environment, in a familiar neighbourhood and amongst old friends and important places.

Undoubtedly, as a society, we need to promote a better understanding. We need to do it in the same way we 'uncovered' cancer in the 60's and 70's - by talking about it, sharing information; getting GPs to identify dementia as a primary cause of death on death certificates (thereby giving a more accurate statistical representation and alerting family members to what has actually precipitated end of life); by encouraging obituary writers to acknowledge the role played in a person's life by dementia.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

Stigma does exist but we believe it is borne out of ignorance of the disease and how it impacts on a person's behaviour. We are reminded of the time when people with a physical disability were stigmatised and

patronised e.g. a carer would be asked 'Does he take sugar?' rather than ask the person with the disability. Yet now legislation has been passed to enable people with disabilities to take a full part in society. We believe that the same process is gradually happening for people with cognitive impairment.

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

As a society, we should be inclusive. We need to take the mystery and fear out of the disease by raising awareness in citizens from an early age, not putting people 'away' when the dementia progresses. Alzheimer's cafes have been popular as part of everyday life in communities in UK and abroad and have encouraged more integration. The media could be used constructively to continue to accurately represent people with dementia e.g. TV and radio dramas (as in characters recently played in *The Archers*, *Coronation St*) and newspaper reports.

Person-centred care and personal identity

Q10 Is the idea of person-centred care helpful, and if so, in what way?

Understanding and applying a person centred approach is essential to the well being of a person with dementia. When we are not person centred, we run the risk of treating a person with dementia as an empty vessel with no rights, no voice and no feelings. Care services that are person centred demonstrably meet the needs of the person with dementia and enhance well being

Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?

We are not sure that we would use that particular expression. There are so many dementias and so many individual interpretations of the disease; each one affecting a person in their unique way. Some people with dementia may not experience a huge change in their core personality; some others may be hugely affected to the point where they are no longer recognised by family and friends as being the person they know.

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

This is a difficult question to answer- a great deal depends on the strength of the pre-morbid relationship. Some partnerships and family relationships can weather any storm, others fracture and fall at the first sign of trouble. Some family members find it impossible to face up to enormous personality or behavioural changes and become estranged. As for respecting prior held or stated values and wishes- we find this virtually impossible to untangle and answer

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

A Guideposts employee with 30 years experience in social care has replied to this question saying 'I have not told the truth on occasions – such as when a person with dementia has expressed a need to speak to a deceased relative, not understanding that the person died many years ago. To tell the person with dementia, repeatedly, that their relative has died causes renewed grieving and is tangibly a painful experience'.

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

On balance, we think that carers err on the side of caution, 'wrapping the person up in cotton wool', out of fear of harm. Carers' motives are usually protective. The concept of a person with dementia taking risks is difficult to accept for many family/carers/professionals.

The balance of freedom versus restriction should be determined by the nature of the risk factor – e.g. being left to cross the road alone when that person no longer perceives or forecasts the effect of stepping out in front of a moving car.

Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

Some restraint has to be in place when circumstances dictate. For instance, allowing a person free access and egress of a building should be permitted, even encouraged - but not when the building design means that the person can walk out on to a busy road. Rather, then, that the design of the building should change to accommodate the person's need to go in and out at liberty but not threaten life. Decisions in this case would have to be taken by whoever is deemed to be acting in the person with dementia's best interests.

We think that the current panoply of legislation makes it very difficult for carers to balance risk, give freedom, employ or withhold restraint and respect the person's basic human rights all at the same time.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

We think that the general education for carers should focus on a person centred approach, alerting all who care to think about the person's

situation and their own needs. Specific education in ethical aspects of decision making would then build on that person centred approach and would help carers to know that what they are doing is legal/illegal and /or ethical.

Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

Taken to its extreme, a smart home with surveillance can be seen as invading a person's privacy. On the other hand it can be seen as liberating the person from the shackles of a very restricted lifestyle by allowing them to move about freely and alerting others when care is needed. New technologies can mean the difference between staying safely in a familiar environment or moving to an alternative, unfamiliar setting (e.g. extra care housing, care home).

Regarding tracking devices: we think an individual might ask this question – 'If I can no longer work out how to get home, would I want my family to be able to locate me?' - and we believe the answer would be 'Yes, I would'. GPS tracking devices are successfully used to keep watch on/locate vulnerable children. I think it is sensible to use technology to help a vulnerable person.

There are some illuminating examples of using technology to stay in communication with family members, see the item about Ken Nixon keeping in touch with his mother: <http://www.nia.nih.gov/Alzheimers/ResearchInformation/Newsletter/CurrentIssue.htm#necessity> – this is one area of technological advance that can be utilised for the benefit of the person with dementia and their families

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

We understand that the word 'duties' in a formal sense refers to duty as defined by current legislation and is uniform across the country (e.g. duty to assess needs of the person with dementia and the carer, duty to provide accommodation by reason of illness or disability and so on). However, the resources available to meet assessed needs can vary enormously around the country and across professional (health /social care) boundaries. As a society, we are failing to meet needs in a consistent way because of these differences.

There are four areas where we think the state owes duty to people with dementia and their families but these areas have not yet been addressed;

- The first is with regard to the treatment of cases where abuse and/or neglect is believed to have occurred. It is quite difficult to use existing 'duties' and 'powers' to investigate and extricate a vulnerable adult, particularly older person with dementia, from such a situation. Whereas the protection of a vulnerable child is more straightforward to address. This situation discriminates against the older person.
- The second area is in the use of 'national minimum standards' (NMS) to judge care in care homes and in a person's own home (home /domiciliary care). Approximately two thirds of the population of residents in care homes have some degree of cognitive impairment yet the standards by which those homes are judged are not dementia specific. Indeed, NMS pay little heed to the quality of care delivered, most standards are quantitative.
- The third is in relation to social care 'eligibility criteria' – problems in this area are being ironed out but we still have staff groups involved in that process that lack knowledge and skill about dementia leading to uneven assessment and provision of services.
- Finally, in the acute mental health sector in particular, the provision of services continues to treat and accommodate together those people who have functional and organic disorders. We believe that this situation is less than satisfactory because both categories of illness require their own speciality services with focused skills.

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

Research should be about making a difference – making a difference in the quality of life that a person with dementia experiences, making a difference in the life of the person caring for someone with dementia.

A recent Guideposts research project, part funded by DH, focussed on improving the quality of life for people with dementia in care homes. The main outcome, a training pack for care homes, requires all staff in care homes to have a body of knowledge and skill that they share so that any person with dementia in the care home receives informed, empathic and consistent care. This is an example of where research and evidence has been translated into practice, making a qualitative difference in care that is delivered.

Funding should be based on the number of people affected by this condition in UK