

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.

Dementia Services Development Centre (South East)
Canterbury Christ University
(Mrs Penny Hibberd, Admiral Nurse/ Senior Lecturer)

QUESTIONS ANSWERED:

Q1

ANSWER:

Changes in a person's behaviour seem to have the most impact. Knowing how to manage the changes is very important and who to contact for advice and information is essential. The general public have little knowledge about how dementia can change the way people react to a person's changing cognitive functions. For example: being able to wait in a queue in a busy outpatients department. This is very stressful for the person with dementia and their carer, the environment is unfamiliar and busy and the reason for being there is often unclear, Information giving at an appropriate level and time is essential at all stages of dementia. To be able to do this there needs to be continuity of care that is accessible and flexible to the needs of the person with dementia, their carer and family. Support requires careful planning with the person with dementia and their carer. Sometimes this needs to be done in isolation of each other but the relationships around both people must be taken into account. A professional relationship should be built up with the person with dementia and their carer as early as possible to diagnosis this should be done with the most appropriate person e.g. CPN, Admiral Nurse.

Q2

ANSWER:

Carers and family members often raise questions about how to manage risk at home. Sometimes this has involved locking the person into their home or restricting their movement. Discussions about how to sensibly reduce the risks to the person with education about the type of dementia the person has can be helpful in managing risk. Practical interventions using things like audible alarms can also be helpful. Ethical dilemmas also arise at point of diagnosis when sometimes the person who is being assessed is not fully aware of the reason they are attending the assessment, disclosing the diagnosis to a family member not the person can also be an issue. In practice it then becomes difficult to build an honest professional relationship with the person with dementia and their carer.

Q3

ANSWER:

Every person with dementia is an individual and will have their own experiences and beliefs. Each individual's understanding will be rooted in these. Language and religious beliefs often open up a different aspect or way of managing. Careful consideration should be made by each professional engaging with a family regardless of ethnic background but specialised information and help may be required e.g. translators, appropriate chaperone

Q4

ANSWER:

There are examples I have come across in practice where the person with dementia has 'forgotten' their background or a certain way of practising. For example eating a certain diet or dressing in a certain way. With empathic and understanding approaches these changes can be managed in a sensitive way but supporting and informing family members is essential.

Q5

ANSWER:

My main interest lies in psycho social interventions but advances in finding a cure or delay in the advancement of Alzheimer's disease looks very promising. My concern is the public's lack of knowledge about the other types of dementia.

Q6

ANSWER:

As early as possible - as long as the person has been adequately counseled and has agreed to the assessment

Q7

ANSWER:

I think dementia has gained a higher profile in the last ten years but remains a feared diagnosis. Most people focus on 'aggressive and challenging behaviour.' People require an understanding approach to people with dementia that is kindly, at a pace they can keep up with and that is inclusive e.g. help in the supermarket equivalent to those who have a physical disability.

Q8

ANSWER:

People are frightened of it. This isolates the person and their carer e.g. when a person is finding using a knife and fork difficult it is not acceptable to sit in a restaurant

Q10

ANSWER:

It has become a sort of buzz phrase and can actually isolate the person with dementia from their carer and family. This is wrong no one can exist without relationships with other people, especially the person and people they know and love best.

Q11**ANSWER:**

It is our responsibility to work alongside that person within that inner self that stays the same. The facts get forgotten but the feelings remain the same.

Q12**ANSWER:**

In my experience this has only had implications when questions about risk to the person with dementia or another person has been raised. It is usually centred around a relationship that is or has become close. Balancing the needs of the other person can sometimes become very difficult and the importance of supporting that person can be critical to both peoples care. e.g. when a carer is not getting any sleep or when the person with dementia thinks a family member has stolen their money. The Admiral Nurse is well placed to support the carer and family member in these cases.

Q14**ANSWER:**

It is essential that the person who knows the person the best is closely involved and that they work alongside the professional team. The professional team must recognise that person's expertise (often the carer who is a husband or wife of many, many years). In my experience decisions that are made by a team of people alongside the person with dementia have the best outcomes.

Q13**ANSWER:**

In my experience the best way to do this has been to talk to the person with dementia to get a 'feel' of how they are managing at that particular time and then to speak to their family and professional team. This way everyone can work together to get the best for the person with dementia.

Q15**ANSWER:**

Early diagnosis is essential for the person with dementia to be able to plan to make these decisions.

Q17

ANSWER:

I think it is important to encourage people to think about their future. Advance directives can then be discussed with the carer for example in the case study cited in the text p.22. This is a dilemma for professionals and the carer but at least you have something to discuss and build upon. In the future I think people should be encouraged to think about different scenarios and maybe make several suggestions of choices they would make. Thinking ahead and taking responsibility for our own health care is new to us and people are still reticent about talking about dementia and dying.

Q19

ANSWER:

This is such a dilemma for professionals and I have experienced many heated debates with students. In reality I think professionals and carers do lie to people with dementia. Sometimes this is done covertly and sometimes as part of the family belief systems. Lies are often cloaked in different words like validation and therapeutic intervention. I know if it was me I would prefer someone to validate my feelings so that I felt safe and cared for rather than telling an absolute truth and place me in a state of turmoil and distress. A great deal of skill is required to manage situation where a person is looking for their mother who has been dead forty years. It is often the distress of the professional or the carer that is the problem, this is transferred to the person with dementia and a cycle of anguish begins. Only with better training, knowledge and support for professionals and carers can we resolve this debate.

Q20

ANSWER:

There is a great fear about people with dementia getting emotionally hurt, physically injured and abused. This is right as we have a duty of care to people with dementia but with good risk assessment the freedom to walk, go out and engage in activities should be encouraged. The wording risk assessment conjures up thoughts of injury let's get back to an affirmative approach to exercise and activity and call it an 'enabling assessment'. We can only reduce risk not eliminate it.

Q21

ANSWER:

There has to be an understanding of what restraint is and carers need a lot of support with this. In a family situation a carer may have to lock the door to be able to safely leave the person with dementia to go to the toilet. Not locking the door may mean the person with dementia has to go into care. A degree of common sense has to reign that incorporates the norm for the person with

dementia and their carer balanced with keeping both people safe and independent. Deciding what is right and what is wrong in these cases takes a sensitive and specialist approach involving the people directly involved and where possible the person with dementia should be central in these discussions.

Q22

ANSWER:

Theory and evidence base can be discussed in a classroom and debated however a specific skill in managing this type of situation has to be practiced and learned from experience. Mentorship and practice based courses may be a solution.

Q23

ANSWER:

In my experience carers and people with dementia are usually open to trying out a range of different types of support technology being one. Access and cost of technological interventions is prohibitive in some areas. Other times it is introduced too late for the person with dementia to learn how to use it or get used to living with it. Some people just do not want to be reliant on a machine and would prefer a person.

Q24

ANSWER:

The ethical debate about who pays for care is important to consider here. Today's older person was promised a cradle to grave NHS service that they are not now receiving. Wives are being stripped of their husband of 50 or more years' occupational pension surely they have a right to some of that money? People struggle to maintain the family home whilst supporting a spouse in a care home fearful that if they sell they will not be able to buy another property and/or leave a legacy to their family. This is not new knowledge but a very, very difficult aspect of practice when as a professional you know that care is inevitable for most people with dementia there is no choice as services in the community cannot provide the 24 hour care and support in end of life dementia care. The state owes people the choice to die in their own home without making an acceptance of services a financial penalty.

Q26

ANSWER:

Health and social care professionals require expert skills in assessment to be able to meet the needs of both people. Sometimes in cases of conflict there is difficulty in finding a resolution often this is due to resources (staffing levels and service provision) e.g. a carer often would like to continue to care at home but is not getting any sleep. There are rarely community services that cover a 24

hour period for more than a short period of time. Services need to be provided 7 days a week and cover the 24 hour period. Continence is another issue that often culminates in a crisis services need to work together to give the right and timely support to families caring for a person with dementia. This means listening to each other and being flexible in how a service is delivered or offered. Carers skills must be recognized as such, working in partnership with a professional that is continuous so that the relationship of trust and honesty is built up is essential. The Admiral Nursing Service provides a good model for this. Often the carers voice is 'drowned' by the professional inadvertently labeling the carer as obstructive or in denial.

Q25

ANSWER:

The Admiral Nurse Service provides a specialist nursing service to carers of people with dementia. Supporting and enabling the carer through developing their knowledge and skills in dementia care can be very effective in resolving conflict. In circumstances where decisions are in conflict with the person with dementia the carer becomes very vulnerable and alone the Admiral Nurse can work alongside them as an advocate and provide support structures. Discussing the future as early as possible with both people is a good way of getting an understanding about what the future holds. Past conflicts often raise their heads as dementia progresses if the professional has a good relationship with the family and has some knowledge of the family background future conflicts can often be avoided.

Q27

ANSWER:

In cases of abuse or continued concern for the safety of one or more people in the household. In my experience this has also been when the cared for has previously been the carer. For example the carer has a mental health problem or physical disability themselves. However I think the situation could often be avoided by early intervention that is continuous throughout the families caring role and sometimes beyond. There is a definite steer away from having families who are 'dependent' on services. This needs rectifying. Patients and families in acute services have high dependency needs for some reason in mental health this is frowned upon. It is time to acknowledge that families and people with dementia do have high dependency needs that need addressing and supporting by professionals. Being discharged from a service and then having to go through the whole system again to get help is just impossible to contemplate for some people others will just not feel they can ask for help. An open service like a GP service is by far more accessible and user friendly.

Q28

ANSWER:

This is about getting to know the person with dementia and the carer. There needs to be consistency in with the professional/s involved to allow a relationship to build up. Sharing information is different for everyone as we are all individual, we learn at different speeds and have different life experiences, relationships, and culture and belief systems. The professional has to be able to 'listen' to what the person with dementia and their family are saying and offer the appropriate intervention for them.

Q29

ANSWER:

It is important to build an evidence base about what works for people with dementia and their families. However the research should be accessible to them and in a language they understand. Research being conducted by people with dementia should be a priority for funding.

Q30

ANSWER:

The ethical process in this country is rightly vigorous and I would agree with the text on p. 36 apart from the argument not to involve people with dementia.

Q31

ANSWER:

No I don't think so. I do think that the ethical processes are in need of review in the amount of time it takes to get a research study approved. This is extremely important as people with dementia wishing to take part in a study may not be able to give consent a year down the line when the ethical approval is finally given.