

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.

Section 1: the experience of dementia

The impact of dementia

Q1

a) Loss of memory

As the person with dementia struggles to recall people, places and events they believe that vital information is being withheld. "Nobody told me" is a common complaint which results in a feeling of isolation.

Loss of memory is the key to confusion as the place where they live is no longer recognised as home (home is often their childhood home).

A husband becomes a father as the husband they remember is "young and handsome" and not the old man sitting in the fireside chair.

b) Paranoia

The person with dementia is frightened and suspicious. They become obsessive about money and possessions such as jewellery and handbags and hide valuable items.

They are often afraid of people and unwilling to allow strangers into the house. They are also suspicious of close family suspecting their motives and accusing them of stealing.

c) Communication difficulties

i) Speech can become unclear and mumbled.

ii) Sometimes the conversation makes no sense at all.

iii) The person with dementia can substitute inappropriate words e.g. "I've lost my handkerchief" becomes "I've lost my nose".

iv) Sometimes words cannot be recalled – names of family members or symptoms of illness e.g. circulation – these have to be written down & kept by the bed or in a pocket.

d) The inability to rationalise

Because the person with dementia cannot make sense of their world the carers cannot give a reasoned explanation which will satisfy and reassure.

The support needed most is more advice strategies to deal with the confusion and anxiety. I appreciate that everyone behaves differently but

I do believe that there are common traits and it seems to me that every carer is learning the hard way from personal experience.

Q2

I believe that a person's background makes a difference.

Privacy: A resistance to strangers in the house.

The quality of care when being washed or sores dressed.

Pride:

An unwillingness to accept financial support or gifts from social services such as a safe electric blanket "We are alright, we don't need help" was often said.

Diagnosis

Q3

It would be helpful to do tests for dementia when memory problems are giving cause for concern especially if other symptoms are emerging. Family members would have a greater understanding and tolerance if there had been an indication that their relative was developing a serious problem.

Personally I would have found it very difficult to discuss dementia with my parents as neither would accept that they had a problem or appreciated that they were losing control.

Person centred care

Q4

This question helped me to reflect on two experiences

- a) When my mother was wandering in the night, I would take her back to her bed but within minutes she would be in my room "tucking me in" and asking if I was alright. She sometimes transferred her illness to me and tried to assume the role of carer.
- b) I often wonder how far my father's behaviour was influenced by his wartime experiences. The gentlest of men became demanding, authoritarian and aggressive towards the end of his life.

On his return from the war in 1946, he was introverted and would not share his experiences although we knew that colleagues in the unit that he controlled had been killed. On his 80th birthday we took my

father to Paris and in a restaurant he heard French voices behind him. He became hysterical and began to curse the French. Soon after this shocking incident he began to have panic attacks and he deteriorated physically and mentally. Perhaps his later aggression was his way of expressing his anger about events that he had 'bottled up' for the major part of his life.

Personal identity

Q5

Until the last couple of weeks of life my parents still demonstrated recognisable characteristics. Some days were better than others but, on a good day, the essence of the person would shine through.

Changes in mood and behaviour support this belief as the various symptoms become more profound or seem to ease a little as something else takes over.

After a T.I.A. my father would be in a traumatised state for a few days but then begin to recover, although never to the same level. He retained his personal identity to a greater extent than my mother (an Alzheimer's patient).

Section 2: How society sees dementia

Stigma

Q6

I have no evidence that society perceives dementia in a negative way. We took my parents into restaurants and to the theatre as long as we could and they were always treated with respect and kindness.

Q7

- a) People living within the family should be included in outings even if this only entails a visit to the supermarket.
- b) People living within a residential care context should similarly have opportunities to interact with the wider world.
- c) Leisure and cultural venues should ensure that access is provided for all forms of disability.

The government's duty to support people with dementia

Q8

- a) I believe that the government should give more support to the Care in the Community scheme so that, wherever possible, people with dementia can remain in their own home.
- b) From our experience Social Services tend to have a set agenda to provide carers for washing etc. and respite for family carers. Unfortunately, since we did not need this support, our names were withdrawn from the register (without consultation).
- c) What we did need was a mental health nurse to advise and support – someone with whom we could discuss problems.
- d) Funding for the ancillary services e.g. physiotherapy, chiropody, dentistry when it is no longer possible to get the person to a surgery.

N.B. We were fortunate to have the support of a doctor from the Community Mental Health Assessment team. She telephoned or called in occasionally to keep in touch and her concern was greatly valued and appreciated. Our GP practice was very supportive in the later stages but it did not have the staffing resources to get involved with dementia from the beginning.

Section 3: Making decisions

Q9-12

- a) On the whole, my parents lost the ability to make decisions and the answer to most things was "I don't know"
- b) The most significant wish for both parents was their desire to live and die at home and this decision was something that my husband and I felt that we had to honour.
- c) Most of the time they took pride in their appearance but, if occasionally, they didn't want to wash or get dressed we learned to avoid confrontation. Often they changed their minds after a few minutes!
- d) It is important to give the person with dementia the impression that they are making the decisions by saying things like "that's a good idea" or "yes I think you're right".

- e) I would not be in favour of Advance Directives as the situation can change so rapidly.
- f) I do not see the need for Welfare Attorneys as a close family relative would be involved in the decision making process anyway. If a mental health nurse had a more 'Hands on' role in working with the family he/she would be able to offer an unbiased view.

Section 4: Dilemmas in care

Truth telling

Q13

- a) My mother had two recurring questions in her later life. The first concerned her wish to go home. The truthful answer to "can we go home tonight?" was "you are home". This repeatedly caused great distress. She would sit in the hall with her coat on (sometimes with her nightdress tucked inside) and pick up the phone to ring for a taxi. She would threaten to get out of the house and wait at the bus stop. After several months I distorted the truth. I explained that the weather was dreadful – cold & wet – and we couldn't go out on such a night. We would stay warm and safe until the bad weather had passed and talk about it in the morning.
- b) The second issue concerned the question "where's your father?" When I explained that he had died the truthful response caused panic as my mother assumed that he had just died and we needed to get a funeral director, put a notice in the paper and arrange the funeral. Gradually I realised that I had to avoid saying "my father has died" because every time she heard this she suffered bereavement all over again. I tried to pretend that I hadn't heard, changed the subject or even said "I don't know but I don't suppose he will be long".
- c) I felt fully justified in telling lies if it prevented my mother going through even more distress.
- d) When my father's behaviour was aggressive I would express anger. He reconciled this change in my attitude by saying that he had two sets of carers/nurses and he didn't like the ones who had been on duty the night before i.e. the stern, cross one*. I went along with this misconception so that our relationship was never damaged and he felt secure and happy in our care.

Freedom of action

Q14

- a) As a carer you have to take responsibility for accidents and ensure that the environment is safe e.g. hand rails, an added banister rail, gate at the top of the stairs. These allow the person with dementia freedom within parameters.
- b) Avoid feeling guilty if the person falls as inevitably happens in spite of precautions.
- c) Engage the person in activities which are unlikely to cause harm but encourage self esteem e.g. laying the table, drying dishes. Do not be critical if the task is not completed to a very high standard!

NB It is likely that an older person with dementia has other disabilities like impaired vision and poor hearing. Mobility problems might increase the need for a wheelchair but this should be resisted for as long as possible around the house.

Restraint

Q15

- a) In the early to mid stages of dementia my mother tried to throw things through the window to attract attention from passers by. We removed ornaments and tried to distract her.
- b) In another period she was keen to wander outside. We watched from a window or followed close behind. We live on a main road and her walking was unstable. Sometimes we had difficulty in persuading her to come back inside.
- c) If we locked the door she became angry and this reinforced her impression that she was being kept prisoner. Having a key in her handbag made her feel more in control and we gambled on the hope that poor eyesight would probably prevent her working the lock.
- d) We had calming drugs but used these very infrequently as we found that with regular mood swings, bad situations would pass. We put some medication in food as swallowing became a problem as the illness progressed. Some medication was given in liquid (syrup) form and my mother liked the sweet taste.

New technologies

Q16

Any thing that enables a person with dementia to remain at home, in safety, supersedes any ethical considerations. The person in the later stages of dementia would have difficulty in remembering instructions and even lose the ability to operate even a simple bell push to call attention.

Section 5: Carers

The impact of being a carer

Q17

- a) A carer must be allowed to do what they think is best for the person in their care even if Social Workers would advise otherwise. I'm particularly referring to the issue of respite which we chose not to accept. Social Services should only intervene if they have severe concerns about the health of family carers.
- b) What we did need was:-
 - i) More written advice on the dementia condition with practical hints on a range of strategies that could be used.
 - ii) More advice on accessing ancillary services.
 - iii) Suggestions for meaningful activities that could interest and stimulate people with dementia. My parents could not engage with television – my mother because of poor vision but in my father's case he internalised the images which became a part of his reality.
 - iv) Carers groups need to be more open minded and accept that some carers do not want self-help groups and social activities but prefer to tackle problems and share success in the home situation.
 - v) Some of the issues raised in question 8.

Confidentiality

Q18

- a) This really doesn't apply to us because my mother totally relied on me and when doctors or Social Services came to assess she just looked to me to answer for her. We never met any resistance in sharing my parents' problems.
- b) I did hate it when Social Services asked to speak to me in another room. This made my mother suspicious that things were going on from which she was excluded and I thought that it showed a lack of respect.

Section 6:

Research priorities

Q19-20

- a) Research priorities should be funded in the order that you suggest in the introduction to this question.
 - b) Research into ways of caring should seek to fill some of the gaps in the current provision for those being cared for at home. The Community Matron Scheme sounds like an excellent idea.
 - c) In Residential Homes it is not funding but education that is required. There is a huge difference between the kind of provision where people are placed in front of a television for hours on end and those homes where staff and residents play games together, do simple craft work and have some live entertainment.
 - d) I would not be happy for anyone in the later stages of dementia to be involved in research.
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Section 7:

Other issues

Q21

One of the issues that I have not covered in my response is the basic human need of a person with dementia to feel valued and cherished.

I found that close physical contact – holding hands, a hug or a kiss worked wonders. A smile or saying “I love you” almost always produced a response.

* - name removed to ensure anonymity