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.

The experience of dementia

The impact of dementia

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?

My wife is in early stage, having been diagnosed in May 2007, after a year or two of increasing memory loss, as yet I am unable to give a personal opinion based on experience. As treatment with Exelon from June 2007 has probably slowed the still steady deterioration in her power of reason.

Diagnosis was confirmed by CT scan.

Q2 What difference (if any) does a person’s religion, culture or family background make?

None that I know of.
Diagnosis

Q3 When do you think a diagnosis of dementia should be made?

Not so early that the sufferer has a full knowledge of the eventual outcome. My wife has never spoken of her concern for the future, and I do not wish to tell her.

Person-centred care as described on page 3, second para.

Sounds like mumbo jumbo to me, myself, being a chartered engineer who worked in a research & development laboratory all my lifetime in industry.

Person-centred care

Q4 Is the idea of person-centred care helpful? If so, in what way?

Care should be given as the circumstances of the patient's identifiable needs require and not be related to their history.
Personal identity

Q5  Do you think that dementia can change people so much that they actually stop being 'themselves'?

YES, AS THE CONDITION DETERIORATES.

How society sees dementia

Stigma

Q6  In your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?

NO STIGMA EXPERIENCED BY MYSELF AS CARER. MOST PEOPLE ARE EXTREMELY SYMPATHETIC AND OFFER HELP, IF NEEDED.
Q7 Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?

So far I am able to maintain an active retirement hobby interest for myself, taking my wife with me, whilst doing most of the cooking, but somewhat neglecting the tidyness of our home.

I have recently been taking my wife to Alzheimers Support Group meetings, which are well run, but am unable to say they are a positive help, as they are only part of my effort to keep my wife involved in everyday life activities.

A name removed to ensure anonymity.

The government’s duty to support people with dementia

Q8 What duties do you think the government owes towards people with dementia and their families, and why?

The government should provide a basic level of care for all dementia sufferers, free of means testing.

Those who have funds to provide a top up quality of life should receive funding from government equivalent to the basic care cost, to and supplement it from their own resources to obtain an increased quality of care, from better quality care homes.

The present system where savings from a lifetime of work are raided by authority, to pay for care, whilst those who have done nothing to save, get the same service for free is most unfair.

I understand the government is considering assessing patients needs and granting them funding to be spent at their discretion, to buy care. Does this mean that the most vulnerable are likely to become "employers" and all that goes with running a small business. What is the government response to this?
Making decisions

The law on making decisions

Q9 How do you think a person’s past wishes and feelings should be balanced with their current wishes and feelings, if these seem quite different? Is the past or the present more important?

Past wishes, express in writing, like wills made when of sound mind must be given priority. Trivial matters, like the example of dressing standards quoted are not worth the upset & fuss they might lead to.

On more serious matters, like spending more than they can afford, others should intervene.

Q10 What do you think family or friends should do if they are worried about the decisions a person with dementia is making?

Use guile where possible, to achieve a more logical outcome. Saving books may be “mislaid”, or even large savings concealed by intercepting mail that draws attention to their existence.
Advance directives

Q11 Should people be encouraged to write advance directives? How should they be used?

Advance directives by definition require the patient to know the future outcome of their potentially terminal illness. If my wife knows now the prognosis, she has never said, and I have never been questioned about it. It would only cause extra worry to her, to write and sign an advance directive.

Welfare attorneys

Q12 What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

Caring for patients with advanced dementia is a "calling" for the best amongst us. When it comes that myself (77 years) or my available/willing family are unable to cope at home, the doctors decisions should take priority, and not be interfered with by those who are unwilling/unable to care for their relative themselves.
Dilemmas in care

Truth-telling

Q13 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

I WOULD NEVER TELL A LIE, BUT PERHAPS ONLY RESPOND WITH AS MUCH OF THE TRUTH, AS IS NECESSARY TO ASSURE THE PATIENT.

AM I ALONE IN NEVER BEING ASKED ANY PENETRATING QUESTIONS BY MY WIFE ABOUT HER CONDITION IN THE YEAR SINCE DIAGNOSIS.

I WAS INVITED TO JOIN AN ALZHEIMER'S GROUP A YEAR AGO, BUT ONLY STARTED TAKING MY WIFE IN THE PAST MONTH, WHEN ENCORED BY A FRIEND WHOSE WIFE IS IN CARE. EVEN THEN SHE HAS ASKED NO QUESTIONS ABOUT OTHERS THERE WHO HAVE MUCH MORE SERIOUS SYMPTOMS.

IN THIS CASE, I BELIEVE IGNORANCE IS BLISS.

Freedom of action

Q14 Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?

COMMON SENSE SHOULD PREVAIL. I WOULD NEVER STOP MY WIFE DOING WHAT SHE DESIRED, UNLESS PAST EXPERIENCE SHOWED SHE WAS INCAPABLE. thus BY definition I ACCEPT THAT ACCIDENTS WILL OCCUR FROM TIME TO TIME.

WE OLDER GENERATION HAVE BEEN BROUGHT UP TO ACCEPT RISK, AND MY WIFE & I LIVED IN LONDON DURING WW2, OUR CHILDREN HAVE ALREADY NAGGED ME TO "MOLLYCODDLE" MY WIFE, WHICH I REFUSE TO DO UNTIL IT BECOMES ABSOLUTELY NECESSARY.
Restraint

Q15 Should any forms of restraint be allowed? If so, when?

Why should dementia sufferers not be restrained, distressing it may be, but on occasions necessary.

New technologies

Q16 Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?

Do not think that technology can solve all problems, except at great cost.

However, if it is affordable, the issue of privacy is no reason to stop the introduction of "smart" housing.

By the time a patient needs "smart" devices to help warn them & others, they are most likely not to feel too worried about the privacy issue, due to their deteriorating state of mind.

Get out funding
Carers

The impact of being a carer

Q17 How can professionals (such as doctors and social workers) help if a carer’s own needs are very different from the needs of the person for whom they care?

I do not see myself as a carer prepared to sacrifice my lifestyle interests completely in order to look after my wife, and at some time will need to take the decision to pass over the responsibility to others, and probably fund it with my children’s inheritance. We all have one life, and know it may be long or short, and finish abruptly or by a prolonged terminal illness. The promise “for better or for worse” is made in expectation of ones partner remaining identifiable the one you married, not thinking at the time, they may finish up not even recognising you 50 or 60 years later.

Respite care to give carers relief for 1 day a week would allow them to continue indulging in their favoured weekend hobby, and appears more attractive than a longer but less frequent relief period.

Confidentiality

Q18 Is it too difficult for family carers to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?

No experience of difficulties at this early stage as a carer.
Research

Research priorities

Q19 What should research into dementia be trying to achieve? On what basis should funding be allocated?

Understanding & treatment working together are the priority. Many of the world's discoveries were made empirically by gifted non-academics, so do not try to understand the brain before trying promising lines of treatment.

Better ways of caring for sufferers can probably be best decided by a proper assessment of existing 'best practice' in various parts of the developed world, and highlighting the most beneficial to patients.

Involvement in research

Q20 What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?

Leave the decision to the consent of next of kin.