

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.

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## **QUESTIONS ANSWERED:**

### **Q1**

#### **ANSWER:**

The aspects that have the greatest impact are the physical and psychological. The physical being the need to care for them as if they were a non-walking infant. Incontinence, toileting, washing, dressing and feeding. Psychologically being their existence as a purely emotional being with consequent empathic needs. The support needed is the meeting of the above. This requires more than one pair of hands, hoisting equipment, commode, incontinence pads, an adjustable bed with cot sides, pressure cushions and mattresses and protective clothing for the carer.

### **Question2**

#### **ANSWER:**

Ethics are a construct of one or more specific ideologies created and amended in the past by individuals with the delusion of the will to power. As I do not subscribe to any specific ideology except a personal one of a mishmash of family, life and death I do not have a code of ethics.

### **Q4**

#### **ANSWER:**

I provide care to one person only and by the underlying assumptions of the question a mono-culture. One aspect of which is attendance at the Roman Catholic mass, which demonstrates her enjoyment of. So I have no questions to raise except one. In my mothers instance of dementia she is infant like. As cultures are learned constructs and my dementia sufferer will continue to travel further back down her own time line would not cultural issues become less and less relevant except to the sufferers family if they remain amongst them?

### **Q3**

#### **ANSWER:**

I have insufficient knowledge of these groups to comment on their understanding. My own understanding is that the subjugation of personal logic to group ideology is an act of self negation and an abdication of personal responsibility.

### **Q5**

**ANSWER:**

Theories and hypotheses are legion amongst the scientific community. The significance of any of them is speculative. Effectiveness is determined by trial and error testing of pharmacological drugs. Knowledge as to the cause of dementia is still lacking.

**Q6****ANSWER:**

When the physician is confident of their opinion.

**Q7****ANSWER:**

There is no such thing as society. There are family, friends, neighbours and strangers and a plethora of organisations in many fields all interfacing at different times with people with dementia. Spending millions of pounds on propaganda (public awareness) is wasteful. Better to provide information to those organisations that interface with people with dementia, so that they can inform those who need to know.

**Q8****ANSWER:**

None.

**Q9****ANSWER:**

People with dementia need stimulation by personal contact otherwise they become more disturbed and their condition worsens more rapidly. I take my sufferer out for runs (wheel chair) in the park, through the streets to the high streets to visit banks and shops, into church to attend mass, out in my car. She interacts with passers-by making her happy. When none of these things are done for some days she becomes very disturbed.

**Q10****ANSWER:**

This approach whilst being ideal, in practice does not happen. My sufferer has advanced dementia. There is no person-centred care provided by the NHS, as they provide no care at all. I provide all the care alone. The limited type of care provided in the past by the NHS was clearly predicated on the basis of what was good for the members of that organisation and only secondarily what was good for the person with dementia. When the need of the patient came into conflict with the organisation and its members needs, it was withdrawn. So the

idea is not helpful, in that illusions are not helpful, as it will not be put into practice unless the relevant parts of the NHS feels it meets their on needs.

### **Q11**

#### **ANSWER:**

Dementia changes a person's identity extensively. Because they have lost a large part of their memory they are living in their own past for most of their conscious and unconscious time. They resurface in the present when stimulated by their environment. In my mother's case she does not recognise me 95% of the time, and applies her brother's name to me 90% of the time. In that other 5% she applies her fathers name to me. In my 5% she also remembers her late husband's name. She has also developed a separate identity from her herself and calls Mary (her name) a separate entity.

### **Q12**

#### **ANSWER:**

In many instances it could destroy relationships and undermine family ties. Caring for a dementia sufferer is a question of choice. I am the sole surviving family member. I have chosen to care for my mother. I can do this because I am free. I have a no partner or children. I have worked for my own self-interests and had no large debts to service (mortgage free). I chose to terminate my employment and dedicate my time to her. If I was not free (a prisoner of other circumstances) I would have been compelled to make a different choice.

### **Q13**

#### **ANSWER:**

I take a different stance to yourselves. The individual should be left as free as possible. The organisation does not put the individual's needs first. Its prime concern is its own needs. My mother's home care was withdrawn by the NHS because the health and safety of its contractors came first. Should she go into a nursing home then the home's interests will come first. She will be subjected to chemical control through anti-psychotic drugs. This will lead to her rapid decline and early death. Ethics are an illusion to enable control to be vested in the organisation.

### **Q14**

#### **ANSWER:**

Best interests are best determined by those in a close position to the person concerned. How can a complete stranger represent an individuals best interests? Professionals may advise, because of their basic level of knowledge, but they do not care about the individual. How can someone truly care about another if they have not experienced part of their life?

## Q15

### ANSWER:

Should is a tyrannical concept. Power resides with those who control access to the treatment. Their decisions are subject to their own ideology. The entrenchment of rules/laws will lead to automatic euthanasia. The BMA's advice on once only resuscitation and its concept of quality of life already leads to some over 80's being left to die in hospitals, sometimes even being starved to death. Better by far for it to be a single individual's decision for which they can be made accountable. Rules, guidelines, laws and regulations destroy accountability and lead to the organization's priorities becoming paramount over all other considerations. A process that proceeds down a track where the switches are all set in one direction only and no alternative route will be considered. This is because the decision maker excludes possible options because he works within an established framework of ideas and procedures (as identified long ago by Lindblom and Sharkansky in their analysis) which leads to a standard option which he uses to pressure family members into accepting as the established practice.

## Q16

### ANSWER:

The Welfare attorney must be the final arbiter. On the grounds that they best know the dementia sufferer. Medical professionals are strangers who have different priorities. Being confined with an organisation and accepting fully its procedures and aims they will follow a preset laid down path in decision making. The needs of the organisation will override that of the individual. Analysts of decision making approaches identified this long ago (Alison, Benveniste, Lindblom, Sharkansky, Morris, Parry and Mohr to name a few). We do not get decisions what we get is decision less decisions. I do not use the concept rational because rational is a deadly concept for the mentally incapacitated. Rationally scarce resources would not be allocated to their needs, when better results can be got elsewhere, and from there it is only a few short steps to mercy killings and then state ordered euthanasia. Disagreements should be left as disagreements. Use of the courts as a form of resolution will ultimately favour the health professionals in nearly all cases as the procedures of the court favour the organisation against the individual. The objective from the court's view, being the speed and cost of the process. Welfare attorneys will be pressurised into accepting the opinions of health care organisations (as identified by Mohr, Eisenstein and Jacob). Lower class and inarticulate people will be hustled through the system as they are in health care and the court, in what ever form it takes, will associate itself with its fellow professional's judgements.

## Q17

### ANSWER:

None. An advance directive is a statement of suicide. If the person wishes to die

then they should take their own life in sufficient time. The personality that made the advance directive no longer exists. We are the sum of our memories. If we lose access to large parts of them, we are someone different to that person. My mother has advanced dementia and she is not the personality that she was six years ago. The role of the medical profession is to apply cures or alleviate pain and suffering. It is not its role to do harm on the orders of a past and vanished personality. People should not be encouraged to complete such directives. Encourage indicates inducement such as reward or punishment for compliance or non-compliance. people should be free to make what ever choices they wish without the minions of the state imposing its passing obsessions on them.

#### **Q18**

##### **ANSWER:**

As I have never read the acts I can offer no opinion. However, I have come upon an issue that makes things very difficult. When diagnosed with advanced dementia it is too late to make a power of attorney arrangement to enable a family member to manage their finances. What is left is the extortionately expense and administratively burdensome order of the Court of Protection. An arrangement clearly designed for large bureaucratic organistions to operate. Expressly not designed for a family member to operate where the dementia sufferer has no realisable assets and an income derived solely from benefits.

#### **Q19**

##### **ANSWER:**

It is NOT permissible to lie to a person with dementia. A relationship built upon deceit is no relationship at all and shows clear evidence of the failure to care.

#### **Q20**

##### **ANSWER:**

I do not err as a carer. My mother's bed is provided with cot bars to prevent her falling out of the bed. This is preventative from experience as she has fallen out of her bed on previous occasions. When sleeping she often sleeps on her side and slides her head off the pillows and over the side of the bed. All activity even when notionally still entails risk. Risk management is the assessment of risk and the evaluation of consequences. The assessment and evaluation are only information inputs to the decision making process. They do not presuppose that action has to be taken. The elimination of risk is impossible. The judgement is on what risks to address and which to accept.

#### **Q21**

##### **ANSWER:**

All people are different and suffer from dementia in different ways, so total prohibitions should not be imposed. The use of chemical restraint is endemic in

the care/nursing/medical industry because it is perceived as the optimum method of risk minimisation. Use of drugs requires a medical opinion and courts do not effectively challenge medical opinion as they acknowledge themselves as not competent in that field. No such self-abnegation is applied to challenging the use of physical restraint. The long term harm to the dementia sufferer of chemical restraint is ignored. The conclusion is that risk to the industry is paramount over the health of the dementia sufferer.

## **Q22**

### **ANSWER:**

No. Who determines the ethics? What are the underlying ideological assumptions of these ethics? There is a secondary issue and that revolves around training. Training is portrayed as some sort of panacea. In practice many "trained" carers forget or ignore their training and revert to their own personal philosophies when working. They acquire manuals and when they pass their NVQ level they never look at their manuals again. Handbooks and instructions are never read or referred to after an initial cursory glance. After a while the trained become indistinguishable from the untrained.

## **Q23**

### **ANSWER:**

The issue is not ethics but cost. Who pays? Who provides? What information is available and from whom? These are the issues. It's about money. The NHS will not pay, the local County Council will not pay. Consequently they do not inform.

## **Q24**

### **ANSWER:**

my personal experience is that the state considers it owes nothing to anybody. It exists above people. It takes money from everyone. Redistributes a minor amount to dementia sufferers and provides no care. No agency of the state is prepared to provide care to mother who has dementia, in her home, nor will any private firm either. The issue is her condition not who pays. The sooner the NHS and County Council is terminated, the better. What is required is medical assessment and an information centre. Money then should be directed direct to the dementia sufferer based on need. Dementia is a medical condition not a social choice. If the NHS will not provide care for a medical condition except on ability to pay then the NHS is a fraud. People should be refunded their national insurance contributions and council tax (county element).

## **Q25**

### **ANSWER:**

The conflict is a level of equilibrium that favours the sufferer and is accepted as such by the carer. The state does nothing except make vague assertions. No

breaks are provided. The level of the attendance allowance is not an income but an insult.

## **Q26**

### **ANSWER:**

They have no ethical dilemmas because they do nothing. They provide no help. An infrequent rare occasional visit is the limit of their interest just so they can pretend they have done something.

## **Q27**

### **ANSWER:**

In my experience it would be impossible for health or social care professionals to look to the best interest of the sufferer rather than their own self interest. So considering another parties interest is incredibly unlikely. Better surely for them to look to the interests of the dementia sufferer rather than take on more nebulous tasks.

## **Q28**

### **ANSWER:**

Confidentiality is the great excuse for the incompetent, the lazy or the downright nasty professional caregiver to hide their performance. Its a control exercise. Those who control the information, control the agenda and therefore the discussion and outcomes.

## **Q29**

### **ANSWER:**

Two outcomes. One, a preventative for use in the early stages and two, a cure that reverses the condition. State funded medical research should be funded on a per capita basis. i.e. the numbers of those suffering from a condition. Reassed every five years. Of course none of this would happen as most sufferers of dementia are old and consequently disregarded.

## **Q30**

### **ANSWER:**

Medical reaerch can only be carried out on the willing. If they lack capacity to give consent themselves then they cannot be used. Non consent has been widely practiced in the past and has only resulted in discrediting the research and the medical proffession. If not then the japanese Nisei units and Dr Josef Mengele would be luminaries of the medical profession. Safeguards would not work. they are just words on pieces of paper and can be disregarded at will by the researchers.

**Q31**

**ANSWER:**

The current legal position, together with the requirements for independent ethical review of research projects, does not prevent any research that I believe would be valuable? Changes in the regulatory framework are not ethically justified. The issue is the cost the product found by the research and who if anyone will pay for it. The methodology to be followed in research is not the prime issue.

**Q32**

**ANSWER:**

No.