

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.

Mrs Lesley Perrins

**QUESTIONS ANSWERED:**

**Q1**

**ANSWER:**

Dementia hits the family unit, not just the person with dementia. When investigating the emotional impact on carers and people with dementia, it is striking how the same list of feelings are identified by both groups. Bereavement before death is a major issue. Family members feel bereaved not only of the person they knew, but of their potential future plans; people with dementia feel bereaved of their very selves (also including their future selves). The unpredictability of the condition (variability of symptoms between individuals and variability from day to day) make it hard to support. People want to know how things will progress and what the time-frame will be, but it is always impossible to say. This means that family members can feel deprived of all sense that the problem is controllable. There is often little need for medical intervention except for drug provision in the early stages after diagnosis, and most Social Services departments won't want to be involved if needs are not yet 'critical or substantial.' Families can feel alone and abandoned. This is especially true of younger people with dementia, for whom services are limited and who may still be at work and have dependent children. Families benefit from having a single contact who can provide information about the illness, financial and legal issues and local services early on, and who can become a trusted person they can turn to later to signpost to other services. Support is about aiming to keep things as normal as possible and putting in appropriate practical interventions piece by piece as the illness progresses. Dementia can divide families, as members often do not agree on how the illness should be managed. Some members find it hard to deal with emotionally and opt out; it is not uncommon for one family member to feel burdened with sole responsibility for support.

**Q2**

**ANSWER:**

Some people with dementia may be 'in denial' about their diagnosis and refuse to believe they have any problem. Others can accept their diagnosis, yet still be unaware of the full effect of their illness on their lives. They can completely believe they are cooking, eating well, cleaning their home etc, but not be doing it. Sometimes, especially if they live alone, it seems necessary to family and professionals to persuade them to accept help to keep them functioning, or to put in services without complete consent or without the real reason for them being acknowledged. This is uncomfortable for all concerned and reduces

autonomy.

### **Q3**

#### **ANSWER:**

My experience as an Alzheimer's Society Branch worker with our South Asian community is that all mental health issues carry a profound stigma and people are reluctant to discuss dementia. It is assumed by people both inside and outside that community that families wish to 'look after their own'. However, I believe the burden frequently falls on a daughter-in-law, and it is not always the case that the women concerned are happy with the status quo.

### **Q4**

#### **ANSWER:**

Real person-centred care needs to be culture specific, as people with dementia often lose later learning and revert to early experiences to achieve psychological comfort and security. For example, a day centre singing songs about the War or reminiscing about life in 50s Britain can further confuse and distress an Asian person with dementia who is already feeling anxious and displaced due to their condition. However, there are 'chicken and egg' problems with this situation - it's hard to begin to fund facilities, employ ethnic workers, put in divided facilities for men and women etc without proving demand; without having these things already in place, it's hard to engage Asian families with local dementia care services.

### **Q5**

#### **ANSWER:**

Stem-cell treatment, as this might allow brain regeneration. Better treatments for alleviating symptoms/slowing progression, combined with an ability to predict who is at risk (comparable with the discovery that treating people with high cholesterol reduces risk of heart attack/stroke). Tests that claim to predict dementia in an individual without effective treatments being available are of questionable value and could be a problem for issues such as insurance.

### **Q6**

#### **ANSWER:**

I think a diagnosis should be made as soon as possible and communicated to the individual. In my experience, although this can be very painful, it gives the person the chance to adapt, the perspective to make the very best of their lives, and the maximum of control over their own future.

### **Q7**

#### **ANSWER:**

Society doesn't understand dementia well. There can be assumptions that both underestimate its impact - 'it's only about not remembering things' - or catastrophise - 'they all get violent, don't they?' I think people with dementia speaking out for themselves could help greatly to promote better understanding. Early diagnosis and encouragement towards self-advocacy can help with this. All organisations involved with dementia also have a moral obligation, in my opinion, to raise awareness about the reality of the condition by every means open to them.

**Q8**

**ANSWER:**

Behaviours that people find difficult tend always to be attributed directly to the condition, whereas environmental factors and the way someone with dementia is treated are of prime importance. Health professionals are often too quick to say 'it's the dementia' when there is a health problem. Workers at our Branch, including myself, at times need to advocate for a person with dementia who seems to be deteriorating, arguing that some other condition is affecting the person that needs investigating and treating. Frequently, we are right. People with dementia in hospital can be seen merely as troublesome patients, when they are actually in pain, confused and unable to speak for themselves. Sometimes the ignorance of nursing staff about the needs of people with dementia is staggering. Even care homes registered for dementia can display remarkable ignorance. I have had families ring to inquire about a room for someone with dementia to be told 'we'll take dementia but not Alzheimer's'.

**Q**

**9**

**ANSWER:**

People with dementia do not lose their experience of life and their sense of belonging, so they can contribute wise views on issues relevant to local communities provided what they are asked about is not tied to the need to remember recent happenings or particular facts. If stigma were reduced, people with dementia might find it easier to talk about how they need to be helped to access local facilities, and to access that help. It's not about INCLUDING them, because they have always been in the community - it's about preventing them from getting EXCLUDED when they need help to continue to engage. A befriender to accompany and encourage them is often all they need to carry on doing what they have always done.

**Q10**

**ANSWER:**

Person-centred care makes sure we concentrate on the whole individual. Background and past life, values, beliefs etc should all be investigated, but they also need to be related to what is going on in the present moment for the person. If we follow person-centred care we are vigilant to observe the person

minutely and to exchange views with other observers. This exactly mirrors the process described for determining 'best interests' under the Mental Capacity Act.

#### **Q11**

##### **ANSWER:**

I believe the majority of people maintain their core identity, but it can be masked by the illness in the later stages and sometimes can only show itself fleetingly. Sometimes when family members feel the person with dementia has lost their personality, they are really talking about social disinhibition, which can be part of the condition quite early on, especially in fronto-temporal types of dementia. This can deeply offend and embarrass them and make them feel distant from their loved one. Often people with dementia are trying to be the person they always were, and carry on doing what they have always done, but their brain is letting them down in terms of actual 'performance'. For example, someone who has been a social hostess may have lost judgement and empathy and her attempts to carry on as before may be disastrous in outcome. Someone who has been highly technical and computer literate may also no longer be able to carry on, and may become enraged because the computer is always 'going wrong', which may be perceived by others as 'out of character'.

#### **Q12**

##### **ANSWER:**

Family members can go through a bereavement process and also be divided between themselves about interaction with the person with dementia and about their care. Sometimes, there can be a loss of connection, where families withdraw support, or cease visiting when their relative is in a care home - 'they are no longer themselves and they don't remember I've been anyway, so what's the point'. Sometimes family don't appreciate the need to choose a care home to meet the individual's need. They can believe anywhere will do because the person with dementia will not notice their surroundings. It is common for families to believe that someone with dementia no longer experiences the same emotions as themselves, whereas the evidence is that the emotional brain remains intact. These attitudes can sometimes be altered by carer education/ good information giving, but often this process is gradual and some people are very resistive to it. It is much easier to believe that the person with dementia is a monster or an empty shell, as this can justify withdrawal from caring. Good family/ carer support at an early stage can help prevent this by putting in understanding of dementia before things get too bad. Families who believe the person has changed substantially tend to give weight to earlier values and beliefs at the expense of observed current needs.

#### **Q13**

##### **ANSWER:**

I think past views and values are important to take into account, but where there is a clear discrepancy between these and current views and needs, I feel the current needs should have more weight. After all, we can all change our views with the passage of time and the change of circumstance, whether we have dementia or not.

#### **Q14**

##### **ANSWER:**

I think the guidance of the Mental Capacity Act Code of Practice with regard to working in best interests offers the right way forward for this difficult circumstance - involve the person with dementia as much as possible; consider all the available options, consulting widely (has anything been missed that would help?); take the viable option that is least restrictive of the person's rights. It's also important to try things out - people with dementia can often find it difficult to imagine how something will be or extrapolate from other experience, due to the loss of power to think logically, which usually happens at an early stage. 'Suck it and see' is often a good way forward, as it enables a person with dementia to comment better and sometimes alters their views. However, this depends upon a reliable and robust review procedure by those managing changes, which is sometimes lacking.

#### **Q15**

##### **ANSWER:**

The diagnosis of dementia should not itself dictate the response. Each individual case needs careful assessment. Sometimes people with dementia who go into hospital with acute illness can seem far more progressed in dementia than they actually are, due to poorly managed pain they cannot describe adequately, delirium, confusion about their surroundings and often depression brought on by the other factors. This can mask their true situation if, for example, they are not eating well and consideration is given as to whether to insert a PEG tube. If the dementia was not clearly 'end stage' before the hospitalisation, then questions need to be asked as to potential recovery of some quality of life. Time and appropriate treatment should be given to enable the possibility of recovery. This does not always seem well understood or easy to cater for in acute hospitals, and specialist rehab units are few and far between. If, however, someone has clearly been in end-stage dementia for a considerable time before a deterioration or illness - unable to sit up, having trouble with swallowing, showing very little response to all stimuli, losing weight despite feeding - it seems right to consider whether, for example, inserting a PEG or giving resuscitation would be appropriate or would create additional suffering for someone who is reaching the end of their natural life.

#### **Q16**

##### **ANSWER:**

Welfare attorneys should prove valuable, not only because they are chosen by the donor as someone they trust, but because usually they will have a deep knowledge of the person who has lost capacity. Because they know them well, they can not only recount past values and views, but may be highly competent at interpreting current feelings and needs, even through observation, if direct discussion has become difficult. In the case of minor disagreements, using the best interests checklist from the Mental Capacity Act Code of Practice should be helpful in seeking more evidence on which to reach a decision. In the case of a major disagreement, I agree that it might help to contact other medical experts, but in the last resort matters would have to go to the Court of Protection.

#### **Q17**

##### **ANSWER:**

I believe most people make Advance Directives because they don't want to be 'trapped' in a life without quality or be a burden to their families. In the case example of Mrs A, neither of those things seem to be true of her present condition, though she may have presupposed that dementia would create such a situation. In such cases, a family member may be able to comment on what the underlying motivation for making the Advance Directive was, which might help inform the discussion about its current relevance.

#### **Q18**

##### **ANSWER:**

The Mental Capacity Act should mean that people with dementia's rights and views are given more attention, which is very desirable, but it doesn't necessarily make caring for them easier. Overriding their choices is often easier. It can be extremely difficult to balance the needs and rights of someone with dementia and those of an equally elderly and perhaps disabled spouse carer. It is also very hard to determine in some instances whether a person with dementia has capacity and is simply making an unwise decision, or actually does not have capacity because they are unable to 'weigh and balance' the consequences of their actions.

#### **Q19**

##### **ANSWER:**

If the person's condition has reached a point where they inhabit a different reality for most of the time (usually the past transferred into the present), and they are no longer able to be re-orientated, then the truth of our reality cannot be grasped by them and is meaningless. It is important to speak to the emotional needs of their actual life experience. However, it is often possible to avoid actual lies - eg it's not necessary to agree that a dead mother is going to come and visit if a person with dementia wants this to happen, but it is possible to talk about the mother and what she means to the person with dementia, and to offer perhaps some reassurance and affection, such as mother might give,

which could reduce the yearning for her return.

## **Q20**

### **ANSWER:**

Usually people err too much on the side of caution - family because they are protective and worried, professionals because society in general has become very risk-averse and everyone feels they should 'cover their back'. Things that need to be thought through in each case: nothing is risk-free; what is the worst that could happen? How likely is it to happen? What would be done to handle it if it did happen? What can be done to reduce the risk? What are the benefits of taking the risk?

## **Q21**

### **ANSWER:**

Restraint should only be used as a last resort because person to be restrained or others are at imminent risk. Triggers for challenging behaviour should be identified, in order to avoid it before it happens whenever possible.

## **Question**

**22**

### **ANSWER:**

Definitely required. Better mechanisms are needed to ensure the adequate training of staff in care homes and domiciliary agencies about all aspects of dementia. It seems that there is very little hold over private care providers to ensure adequate staff training, even in the highest registration of EMI Nursing Care. Licensing for care of people with dementia by any agency should depend upon demonstration of staff training levels, as this would force providers to address the issues. Recognised training modules in dementia could also be developed for Social Services Care Managers, District Nurses etc that could include the ethical issues. At present, such workers seem to build knowledge of dementia needs by gathering experience, which makes it very variable from one worker to another. National Alzheimer's Society could have a strong role in training provision/ development, but cannot enforce basic standards.

## **Q23**

### **ANSWER:**

I think there are rightly many concerns about reduction of privacy, dignity and freedom of action. However, I think this could be helped if more people with dementia are involved in discussing their care at an early stage. From responses I have read in the Alzheimer's Society national newsletter, some people with dementia find the idea of tagging, for example, distasteful, while others are willing to embrace it if it offers the possibility of continuing to go out alone and being safe. Each individual has views about what type of care intervention they

are prepared to accept, just as is the case for people who do not have dementia.

#### **Q24**

##### **ANSWER:**

A duty to inform and facilitate from an early stage, as this gives maximum power and choice to people with dementia and their families to deal with their own situation. A duty to provide rigorously enforced standards to ensure high quality of care from private providers and within local authority and NHS services. Many families want to support a relative with dementia, but there often is insufficient range and flexibility in the services available to assist them in their aim. This is particularly true when it comes to younger people with dementia.

#### **Q27**

##### **ANSWER:**

Where the caring situation is in danger of failing because of family issues/dynamics. Where two people are mutually dependent still, physically, emotionally and mentally. eg Respecting marriage vows can have paramount importance for some couples, so that separation is deeply unacceptable. It depends on the relationship. Not all people want or should remain together when one of them has dementia - for others it will be devastating to separate.

#### **Q25**

##### **ANSWER:**

Couples and families are hit as a unit, so support from an early stage should be provided to them as a unit, wherever possible. This can help reduce conflictual situations later. Each involved family member needs to ask 'What part can I/ will I play?' and try to answer that honestly and realistically. The balance of rights for each affected person needs to be considered. The person with dementia has specific vulnerabilities which may be seen as a reason for prioritising their views and needs. However, sometimes a person with dementia's lack of insight and empathy with their carer's situation can lead to that carer being trapped and unheard and to them losing their rights. When a family is well informed about the effects of dementia, they are more likely to accept and understand and reach good joint decisions later, but this is never guaranteed. I think there is a debate to be had about whether disputes are resolved by having opposing advocates for different members, or by a more mediatory compromise-seeking approach.

#### **Question**

**26**

##### **ANSWER:**

It can be hard for them to do justice to the balance of rights, but they have to try. For example, it does not pay to erode a carer's rights to the point where

they do not behave well to their loved one or become seriously ill. Trying out different types of solution, where possible, can help -the effects of trying something in reality can produce unforeseen results and changes of view and sometimes help to move a situation on beyond the impasse.

## **Q28**

### **ANSWER:**

I think family carers are often given too little information in some situations, particularly acute hospitals. This can lead to the person with dementia's interests not being adequately addressed. People with dementia who get on with their families often want them involved because they know they need a trusted supporter- can they not be asked if information should be shared with them? Could this not be addressed as an issue early on, near to time of diagnosis?

## **Q29**

### **ANSWER:**

Effective treatments. Preventative interventions. Improvement of care practices. Funding should be balanced between the aims of long-term cure/ treatment and care interventions that might provide benefit to those who already have the illness.

## **Q31**

### **ANSWER:**

I don't know of anything valuable being prevented.

## **Q30**

### **ANSWER:**

I think it is important that research is done into the later stages of the illness when it is hard to take direct evidence from those who have it. This is particularly so with testing out care interventions. Much is still unknown about the experience of late-stage dementia, and more knowledge might directly improve the life experience of people who have lost capacity to give consent to research. Carers can be the arbiters in many cases. Some research is also conducted on the premise that 'consent' from the person with dementia is an ongoing issue. Consent can be given by a carer and then implied from the person with dementia if their behaviour does not indicate any distress being caused to them. Behaviour should be monitored closely during any research procedures and involvement in the programme should be suspended for the timebeing, or terminated, if the person with dementia exhibits distress, a desire to leave the room or similar.

## **Q32**

**ANSWER:**

I think the issue of long-term denial of the condition by a person with dementia is very difficult. If they are not accepting facts given to them about their diagnosis and the evidence of its effects, does this have any bearing on a decision about mental capacity? Are they unable to weigh and balance all the information necessary for deciding whether to take or refuse help that is offered, or are they merely being 'unwise'? If someone is living alone and gradually failing, but honestly believes they do not have a problem and that they are caring for themselves fully, this is very hard to deal with. Persuasion to accept services is the only way forward. Sometimes this works eventually, if you keep re-offering every so often, but sometimes it completely fails, as the person concerned genuinely cannot see any need. At present, family members and professionals can be reduced to standing by and watching until the person either puts themselves at imminent risk or becomes ill from self-neglect. Often, they will get a UTI or chest infection and be admitted to hospital. Attempts are then made to prevent them from going home without a care package, which may work. However, sometimes this is a misuse of hospital admission, because it is expedient to admit them rather than treat at home and continue the difficult situation, and sometimes they get stuck in hospital for an inappropriate length of time while things are sorted out, deteriorating or becoming institutionalised. None of this feels satisfactory and is particularly agonising for worried family members, but it's hard to see a better way forward.