

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.

Associate Professor Robert Jones

What is dementia and how is it experienced?

Dementia is a chronic irreversible loss of cognitive ability. In itself it is a lack, a form of disability. It is perhaps subject to more stigma and fear than other disabilities, but it should still be seen as a disability. As with other disabilities it can be the occasion of positive changes and opportunities, but these should not be romanticised. In itself it is an affliction that should be addressed by medicine and research and if good sometimes comes out of it, this is indirectly, not directly. If a drug therapy could alleviate the symptoms of dementia this would count as a great benefit (though, as with all therapies, it would require investigation in relation to cost, side effects etc.). Concomitantly, if a drug caused someone to suffer dementia, the person could reasonably sue for harm he or she has suffered. Dementia is a harm.

Nevertheless, while dementia is a form of disability the person with dementia is still a person to whom respect is due. This includes, respect for the inviolability of his or her life, respect for the decisions he or she has made, and concern for his or her well-being. The movement for disability rights has often identified causes of harm which stem not from the practical difficulties of the disability itself, but from the attitudes of others who fail to make reasonable adjustments. For people with disability, the problems of stigma and discrimination may be as significant, or even more significant than the inherent practical and medical problems they face. This is so in relation to disability generally and it is so in relation to 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 by people with dementia and those caring for them?

In my opinion, the greatest impact from dementia relates to the problem of caring for oneself (i.e. maintaining independence where possible) and of being cared for (accepting help, being in an appropriate and desired environment, support for the carers etc.). My impression is people fear loss of independence, fear being a burden, fear 'going into a home'. In many cases these fears relate to issues which can be, but which are not being, sufficiently addressed.

Palliative care is now an area with its own canons of excellence and it is recognised that excellence of care is possible in this context. Despite the fear and stigma of death, hospices are highly regarded and professionals are respected. It is an area of practice that attracts professionals. This is not to say

the problem of end of life care is 'solved' or, even for those who go to a hospice, that all receive the care they need. It is, however, to draw attention to the development of a medical and social model that has succeeded in large part in overcoming societal and professional stigma in what had been a 'Cinderella' discipline – care of the dying. It is striking that there is no real equivalent to this in relation to chronic dementia care. It remains a Cinderella discipline. It lacks well-known centres of excellence in addressing need, which could overcome stigma. Provision varies, but in general neither support for care at home nor the variety of sheltered and 'care home' provision is such that it allays people's fears.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

Those ethical issues that I have come across in my own experience are covered later in this consultation document. Key would be how to balance the needs of carer and person with dementia, at what stage to think of a care home and the personal guilt involved in that, and the issue about how to prevent someone from wandering off. However, I would also say that even my own limited experience (three people in different contexts) dementia affects people in very different ways and the issues involved will also vary.

Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

I am sure that there are different understandings, but I would also stress that there is great variation between individuals, in their attitudes, their problems, their personal relations, their family situation etc. If there are typical understandings found in certain ethnic or cultural groups it will also be important not to assume that these are homogeneous, any more than they are homogeneous within the group with which we are familiar.

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

I have not given this sufficient thought, but I am sure there are such issues in relation to expectations of care, different priorities, issues of communication/misunderstanding and many other areas.

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

I think there may be future developments in relation to early diagnosis and symptom alleviation, and there may be increased knowledge of prevention, but I am unconvinced that there will be anything like 'cures' for most forms of dementia, and so the number of people with dementia is set to increase. I think that care of those with dementia is less about medical alleviation, or even helpful gadgets, and more about establishing patterns of excellent social care within which medical and technological helps can find their place.

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

I think that the issues in relation to dementia are not different from those involved in testing for other diseases. Some people do not cope well with the knowledge and may wish to defer knowledge. This should be their choice. More fundamentally, knowledge of diagnosis (which will involve various parameters of uncertainty) should certainly be accompanied by adequate and face-to-face provision of information by a medical professional and discussion about what this means for the future.

Early diagnosis offers opportunities to plan and also allays anxiety about not knowing what is happening. This in general is a good. Many of the drawbacks of early diagnosis relate to stigma and fear and to the lack of a hopeful model of what it would be to live well with this disability. These areas should be addressed directly rather than be used as a reason to avoid the issue.

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

In my experience dementia (and something similar could be said of mental ill-health), is the subject of enormous and irrational fear and stigma. The worse case is taken as the mental image of this state, and often the worse examples of inadequate care. In my teaching, it is not uncommon to hear students say that it is better to be dead than have dementia, or even that those with dementia should be subject to involuntary euthanasia.

As an aside, I think the movement to find therapies for conditions such as Alzheimer's, which cause dementia, has sometimes been conducted in a way that compounds stigma. I have seen things written, in relation to stem cell research for example, that has seemed to imply that this particular disability is so bad that it is unbearable. Hence any effort to find a cure is justifiable. As I made clear at the outset, dementia is a disability that should be addressed by medicine and research, but as with other disabilities it should not be implied that life with disability is not worth living or is sub-human or is worse than death.

The Australian academic Christopher Newell has explored some of the ambivalence among the disability rights community to some of the rhetoric and activities of Christopher Reeve in relation to stem cell research. This is because

Reeve focused exclusively on 'cure' and not on making the best of living with disability. I do not have the reference to his paper to hand but would be happy to find it if the working party were interested.

I am aware that stem cell research is itself controversial because of the embryo issue, but even in relation to wholly uncontroversial research there is a tension between putting money and effort into 'cure' and putting money and effort into 'supporting those with the disease (and their carers)'. My view is that, certainly in relation to dementia, the main emphasis should be on support.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

I have addressed this above. I think it is key but to address the stigma issue it will also be necessary to establish models of living well with dementia and models of excellence in care for people with dementia, at home and in more supportive contexts.

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

As with mental ill-health a key part of stigma reduction is integration in society. Indeed what is suffered is as much an alienation from the life of society as an alienation from the individual life of the mind. The mind acts in the public realm (a philosophical insight of Wittgenstein). There will be people who will need very supportive environments, but the ideal should be to integrate the people and the institutions into the life of the community. This is part of a just and inclusive community and is an important element of what some philosophers and theologians term 'the common good'.

An example from my experience: a brother in a religious community in which I lived suffered from very significant dementia. He did not know the date or even the day of the week and could not follow public events. His conversation was mainly limited to 'small talk' – reflecting back what people had said, talking about the weather, enquiring after people's health etc. I do not think he would have been able to make big decisions. Nevertheless, he continued to do some useful work, help with cooking and do washing up etc. He also served at all the Masses (the responses and his role were very stereotyped and not difficult to do). He was also taken out to visit isolated people in the parish, to speak with them. It was work he had been doing for many years when he was in good health and his increasing disability did not prevent it. He had a very pleasant manner and was well liked and people looked forward to his visits. He would also take a regular walk (always exactly the same route at the same time) and was known in the town. The main practical problem was, as he continued to decline, that he occasionally wandered off and, when outside his familiar context, did not know who he was. There were some occasions that were traumatic for him and his religious community. He died around ten years ago and his funeral was very well attended.

Clearly this is a unique case, both in terms of the network of support and in terms of the disposition of the person. He did not have any major change of personality (as some suffer from). In fact his personality served him very well. For the most part, he was not greatly distressed by his declining ability. He would sometimes be frustrated, but he continued to enjoy his life. Things that mattered to him – human contact, a routine, the friendship and respect of people he knew, and even some way of contributing practically to the community, were still there. I emphasised at first that every individual is different, and people are different in how dementia affects them. Nevertheless, what this example shows is that it is possible to be active, be integrated in the community, and be engaged in the life of the community even with significant levels of dementia. [I do not wish to imply that those who can no longer engage actively or ‘contribute’ do not have a life worthy of living, in a utilitarian sense. Human dignity is not dependent on contribution or activity or powers. Nevertheless, to flourish people should be given appropriate avenues of activity according to their ability and not assumed a priori to be incapable.]

It seems to me that what are lacking first and foremost are a variety of models, applicable to different people in our current society, for what it is to live well with dementia and what is involved in excellent supportive care. It is not simply that we do not provide this care or cannot afford it for everyone. My view would be that, we do not yet have an adequate understanding of what ‘excellence’ would involve here. When this is identified it will surely have a place for integration in community life as far as is practicable.

Person-centred care and personal identity

Q10 Is the idea of *person-centred care* helpful, and if so, in what way?

I am no expert in this area, but what I have been trying to articulate could be called person-centred care. Certainly it would require a sense of the human good that was more than medical.

Q11 In your view, to what extent is it correct to say that dementia changes a person’s identity?

No it is not correct to say this.

In some cases, even in severe dementia, the person’s character is largely unchanged or the person becomes ‘more like what they are’ (more vague, or more happy-go-lucky, or more careless and inattentive to hygiene, or more irritable, or more suspicious, or more fastidious about appearance etc.). However, in other cases the personality changes quite drastically, and in a way that is not simply derived from previous habits and character. This is seen, for example, in relation to disinhibitory behaviour. In this case there is a change in personality which may prove troubling for the person and for those around him or her.

It would be wrong-headed, however, to say that such personality shifts change the person's 'identity' in any deep or philosophical sense. Is it the case, for example, that the person with dementia is no longer entitled to a pension, as it was earned by a 'different person'? If the person with dementia spends money from the bank account he or she previously set up, is he or she engaged in 'identity fraud'? If the personal identity has changed is it the case that the sister should say 'I do not have a brother' or the son or daughter should cease to visit or support in any way because the person was now simply an unrelated person? Mental ill-health and mental disability can affect personality but they do not change personal identity. To imagine that 'personal identity' changes is a misleading fiction that generally cannot be applied consistently and where it can be applied, often has consequences that are inhuman and unethical.

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

See question 13 below.

Making decisions

Q13 When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

When I asked two groups of people this question there was in each case a dramatic split between those who thought that (on the whole and on average) the present state should matter more and those who thought that (on the whole and on average) the past state should matter more. Both groups divided around fifty-fifty on this. I am not suggesting this exercise was a scientific test of opinion, but it showed me that people have different concerns and intuitions.

By and large those who were more concerned about the present person were concerned about the danger of neglect or withdrawal of treatment which might have been based on a prejudiced or negative view of (mental) disability. They did not want care to suffer because of unwise or wrongly made decisions of the past.

By and large those who were more concerned about the past person were concerned about the projects, values, commitments etc. and the meaning people found in their life and their choices.

This may be illustrated by two examples:

- 1) A woman has had a bad experience nursing her mother and signs an advance decision to say that, if she had dementia and had a chest infection she would not want antibiotics. Later she develops Alzheimer's and loses the ability to make serious decisions about her care. In other respects she is not greatly distressed, receives good care and sees her

daughter twice a week. She subsequently develops a chest infection and has difficulty breathing. She continually plagues the carers and any doctors she sees, asking for 'something to make her better', or for 'a pill for her cough'. Her daughter argues that they should give her antibiotics if they will help the symptoms, because she can see that is what her mother currently wants.

- 2) A man who is a Jain and has always been a vegetarian gets taken into a care home. He has not married and his extended family are not in the UK. His brother visits occasionally. At first, in the care home, they give him a vegetarian meal, but as his condition deteriorates he ceases to notice what he is eating. One day they are short of vegetarian options and offer him oxtail soup. He seems happy enough to eat it and so they cease to provide any special diet for him. When his brother finds out he is outraged and complains that this is not what his brother would have wanted. The home say that they will reintroduce the vegetarian regime, but in any case there was 'no harm done' because he was 'quite happy' with the food he received.

In the first case my intuition is that the current views should outweigh the past views. This is in part because it is a matter of life and health (the present person's life and health!) but also because of a suspicion that the previous decision was made on the basis of a negative value judgement about life with disability.

In the second case my intuition is that past views should outweigh the current and that the person's overall commitment to a particular way of life should be respected even after he or she has ceased to be aware of it. This is in part because the decision involves a commitment to a recognised good and a stable pattern of practice, but it is also influenced by the fact that respecting the past view will not do him any harm.

The model of autonomy influenced by Locke and other philosophers is an abstraction that does not function well here. Indeed, the same considerations which encourage unexamined deference to the 'autonomy' of the person founder on whether the future person is the 'same person' in this Lockean sense. I have said above that I think that there is no change of 'personal identity' but this is because I do not identify the person with the changeable personality. However, for this very reason I think that advance decisions should not be given an 'absolute' respect unrelated to whether, for example, they are harmful to health and based on negative value-judgements.

I think the MCA 2005 is correct to say, in general, that both past and present views should be taken into account. I further think that whether one or the other predominates should depend on other goods or principles, including the inviolability of life, the respect for the dignity and equality of people with disability, and the rightful desire of people to make commitments in life.

I think that it is, in part, anxiety about life-ending decisions that makes people wrongly isolate the current person from the past habits, commitments, and decisions of that person. If proper safeguards are in place to ensure that patients

to not come to physical harm as a result of unwise or wrongly-based prior decisions, then it will be easier to achieve a consensus that it is right to include the past perspectives of the person into the understanding of current best interest.

Q14 What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

There should be some gradualist understanding of capacity so that if it is missing, but only just, then current views should be weighed very seriously. The example of minors who lack capacity may be illuminating here. The more they understand the more seriously their views should be taken into account, even if they lack legal capacity.

Q15 How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

Dementia will often affect ability to make decisions about life sustaining treatment, and will therefore affect whether a written document or an attorney is to be consulted.

However, the fact of dementia, or any other disability must not be given as a reason why life is not worth living and therefore treatment is not worthwhile. The stigma associated with dementia makes this group very vulnerable to wrongful and lethal discrimination in relation to life-sustaining treatment.

Q16 What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

The Mental Capacity Act 2005 and the associated Code of Practice set out legal powers and appropriate use. It is essential to note that the attorney should make a decision according to what he or she thinks is in the best interests of the person. The first recourse in case of disagreement should be an open discussion about what is in the best interests and why. This should uncover any misunderstanding in relation to the prospects of treatment and also should clarify whether the disagreement is based on a negative value judgement. The MCA is clear that a best interest judgement in relation to withdrawal of life-sustaining treatment must not be 'motivated by a desire' to bring about death.

See also Q 17 below.

Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

Advance decisions are a useful way to assess the past views, wishes or opinions of a person. Even when they are not directly applicable to the situation (so as to be binding legally) they can help the healthcare team make decisions. This is also true of a 'statement of wishes and feelings' which is referred to in the Mental Capacity Act 2005 and the associated Code of Practice.

If the advance decision is valid and applicable to the situation, and there are no reasonable grounds to doubt its validity and applicability, then it is illegal to give treatment. This seems an unnecessarily strong and dangerous law by which people can make unwise life-threatening decisions without any chance to review them at the time they will come into force. The likelihood is that even invalidity or inapplicable advance decisions will be followed, as the path of least resistance (another example of 'defensive medicine', i.e. medical decisions based on defending the doctor from sanction rather than on the best interests of the patient) and this also could lead to useful treatment being withdrawn.

In relation both to attorneys and to advance decisions my own view is that the powers given are too strong and do not allow enough latitude for professionals to make exceptions in order to prevent harm. I would not recommend making an advance decision, though I would recommend making a 'statement of wishes and feelings'. If someone wished to appoint a health and welfare attorney I would recommend that they exclude withdrawal of life-sustaining treatment. An attorney without this extra power would still be consulted but would not have the final say. A general problem with attorneys is that each person thinks he or she is a good judge of character, but people frequently make bad judgements in this area. They sometimes appoint unwise people or even people without their best interests at heart. This is why I would not recommend as a general rule that people should appoint attorneys and why I would recommend, if they do, that they not include withdrawal of life-sustaining treatment. This seems to me a wise general rule.

Further reflection on these topics is provided in *The Mental Capacity Act: A Practical Guide for Catholics*.

Q18 What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

I have very little knowledge of the *Adults with Incapacity (Scotland) Act 2000* but what I remember thinking when I came across it was that it seems more cautious and better framed than the *Mental Capacity Act 2005* in relation to allowing exceptions to the binding character of advances decision.

I have spoken to a nurse who works with adults with learning disability who considers the MCA has helped greatly, clarifying when consent is needed and who can give it, and setting down the presumption that every adult has capacity until it is shown otherwise (and not simply because they have a certain condition).

I have spoken to an intensive care specialist who is less confident of the situation now than he was before. I think he was anxious about attorneys.

I have spoken to a nurse who works with people with dementia who complains that the slow working of the IMCA system has led to patients remaining in inappropriate care settings (in hospital) when there was only one obvious place that could care for the patient and a place was available, but this could not be done until the IMCA's report was received.

These are anecdotes but I suspect that the Code of Practice may need to be revised in the light of experience.

Further reflection on these topics is provided in *The Mental Capacity Act: A Practical Guide for Catholics*.

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

There is an important ethical and human difference between 'not to tell the truth' and 'to lie'. It is not always appropriate to tell someone everything you know on a topic. The time might not be right for a careful conversation, other people's confidences may be at stake, the person may not want to know everything. Openness about information is a general virtue but it has all kinds of limits in particular circumstances. This is as much true for someone with dementia as for anyone else.

There is all the difference in the world between tact (and care in giving out information) on the one hand and lies (giving misinformation). Giving misinformation is disrespectful and fails in the virtue of honesty. In one of the groups on this topic someone raised the possibility that 'going along with' someone's delusional ideas could sometimes be a way to find out what his or her concerns were. I have some sympathy with this approach, but I still think that people should carefully avoid affirming what they know to be false. If I were in hospital with dementia I would not expect people to tell me everything but I would not want to be lied to.

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

I think when caring for someone and taking responsibility there is a natural tendency to take fewer risks than one would in one's own case. As a general view I think people should be more cautious (just as one should be cautious if looking after someone else's property) but complete avoidance of risk is an

impossibility and the desire for it is a vice. Risk should be justified in relation to freedoms and other goods that the person would enjoy, and also in relation to the past views and attitude of the person.

Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

The law should allow restraint only in very restricted circumstances. I do not know the MCA and Code of Practice in detail on this issue but clearly it is an ethical question to which the working party should pay close attention.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

This may be helpful but there it is difficult to achieve consensus in ethics (this is a challenge for the working party) and care would have to be taken that any ethics training would be well-founded, embody a consensus and/or reflect a range of ethical views, and be of practical orientation. That said, I think most professionals value opportunities for appropriate training and development and opportunity to reflect on the ethics of care would I imagine, be welcomed by many.

Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

There are clearly issues here in relation to privacy, and also in relation to stigma. I have already argued that what is lacking fundamentally is an appropriate model of excellence of care for people with dementia. If this were established then there would be a test and a context for evaluating and promoting appropriate use new technologies.

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

People with dementia have certain basic needs to flourish as human beings. They are equally members of society and society exists as much for their sake as for anyone else's sake. Dementia care should be balanced against education, policing, public health and acute health services, and other demands on the public purse, but it should not have a lesser call on those resources than children, workers, those in need of acute care or than other chronic conditions.

There seems, in the case of dementia care, to be a mismatch between the great anxiety people have about this condition, and the great need for quality care, on the one hand, and the priority it seems to have in relation to spending on the

other. In the case of dementia the need for social care is at least as pressing as the need others have for medical care or for education.

The needs of carers

Q25 How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

While maintaining an adequate quality of care (however this is delivered) the needs of voluntary carers such as relatives should have relative priority over the needs of the person with dementia, both because this is necessary for the sustainability of care, and because the carer is a person too and has significant needs.

Q26 What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

The role health and social care professionals play in resolving such conflicts will depend in part on their ability to supply what is necessary to make care sustainable and on their concern for both carer and for the person with dementia.

Q27 In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a *couple* (or of a household), instead of concentrating solely on the interests and needs of the individual?

This seems generally appropriate. Often enough the spouse is involved in providing care and/or will have significant needs herself/himself. Unless the person is estranged from the household then the good of the individual will, in part, be constituted by the good of the household. This is not to say that there will be no consideration of individual good or of conflicts of interest, but is simply to say that evaluation of need should include attention to the human context of care.

Q28 From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

I do not know from experience but if I were caring for someone then I would certainly want to be kept properly informed and would consider counter-productive any measure of confidentiality where the day-to-day carer was kept ignorant.

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

I have contended that the greatest need for those with dementia is in relation to excellence of social care, and of medical alleviation and technological assistance in relation to this model of care. Research in dementia should therefore be directed towards identifying and promoting excellent care, and secondarily to methods of alleviation and long-term investigation of causes, prevention and therapy. Funding should reflect the number of people with the condition and the impact on the lives of those people and their carers, while balancing it with other research needs. On this basis dementia seems under-resourced.

Q30 What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

Consent is not the only issue in research ethics, but the requirement of informed consent provides an extremely important bulwark against abuse of research subjects. Special care therefore needs to be given to research on individuals who cannot give consent.

The Mental Capacity Act 2005 and the Code of Practice lay down some guidance which I have not studied in depth. My initial impression was that the balance was about right. An important safeguard is that research should not carry on if the person displays by his or her behaviour an unwillingness to take part.

I consider very sinister current proposals in the Human Fertilisation and Embryology Bill 2007-2008 to amend the MCA 2005 to categorise using tissue to create clones or hybrids as 'non-intrusive'. In general terms if it is known that a significant proportion of people would strongly object to a procedure, then it is wrong to presume consent to do it. This is using people without their consent as a source of raw material, which is highly objectionable.

Q31 Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research which you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

I am sure that without ethical restrictions at least some research could be done which would bring benefits more quickly or with less expense. The same could be said of research on people against their wishes (for example prisoners or asylum seekers).

In one way the potential for using such people for research could be seen as an opportunity not to be wasted. On the other hand disability, disease, and death from some cause or other will always be with us and eventual future consequences should not undermine the treatment of people in the meantime.

For in the broadest sense we will always be 'in the meantime'. There will always be more research to do, and decisions to be made.

There must be some defence of the present good especially of vulnerable people who will not object themselves. I think that research can and should be done within rigorous ethical limits and that this research will eventually reach the same goals, though not always as efficiently or cheaply as cutting ethical corners.

Other issues

Q32 Are there any other ethical issues relating to dementia that we should consider?

There may be specific issues in relation to assisted feeding (both tube feeding and spoon feeding), which is understood differently by different groups, and indeed by different individuals, and should not automatically be assimilated to other kinds of treatment or care.

There may also be practical (and resource) issues in relation to spoon-feeding, speech and language therapist recommendations about safety (I have heard it argued that these can sometimes be too risk averse – this is worth looking at) and the burdensomeness of intubation (nasogastric or PEG) for people with dementia. There is a book by Alan Bennett ('untold lives') in which he alleges that his mother and other residents in a care home are 'slowly starved to death' as a result of lack of staff to spoon-feed them. This deserves investigation.

The issue of withdrawal or withholding of tube feeding (with or without an advance decision) in the case of dementia is also one that may deserve special attention.

As an aside I have long harboured the suspicion that inadequate diet may exacerbate dementia, a theory I rashly extrapolated from the case of my grandmother. I have not investigated this in the literature but it may be that there are various 'lifestyle' elements to addressing dementia (diet, exercise, mental stimulus etc.). If so this raises questions of choice, adequate information, and availability of appropriate levels of care.

The measure for all these issues is living well with dementia and excellence of care.

