

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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What is dementia and how is it experienced?

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?

Aspects of dementia having greatest impact

The relentlessness of the condition and its component parts

The loss of identity and personality

Inability to communicate effectively

Aggressive and anti-social behaviours

The support people with dementia need is

specific people to take a personal and ongoing interest in them, building on knowledge of them and helping to make sense of their present confusions and behaviours in the light of their previous realities

expert support to facilitate the protection of relationships with loved ones

security which balances safety with as much of a sense of freedom and autonomy as possible

The support carers need is

effective training

a helpline for times of crisis

effective and timely respite

ongoing support

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

Other than the ones in your report

A documentary screened on BBC on 20 May called 'My Mum and Me' which represented a violation of the mother's privacy (filming her naked, being incontinent etc) and implying her consent by letting her see selected parts of the video and seeming to approve even though her dementia was quite advanced.

Volunteers becoming befrienders of people with dementia but a) not understanding or respecting the importance of confidentiality or b) not being given sufficient information to care effectively or c) being inadequately trained.

People with dementia wanting to go out but insufficient staff to take them. Frustration building spilling over as aggression which is not understood, resulting in further restraint.

Inequalities between postcodes with drugs to slow down the progression of the disease available in some areas or for some patients but not others.

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?

It should be tailor-made for each individual with those who know the person with dementia best contributing to the consultation as to timing and extent of disclosure. Families and GPs will have insights into the past responses and preferences and wishes of the patient which should be germane to the decision.

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?

Society perceived it as something to be feared, dreaded, hidden. A form of madness which also leads to a loss of inhibition and unsocial behaviours.

We do indeed need to promote a better understanding of dementia. This might be achieved through various channels: eg

films and videos which explain the distorted perceptions of the person with dementia (ie removing the irrational and threatening elements). The dementia unit at Stirling University produces such aids.

training sessions for anyone coming into contact with dementia in any capacity

short adverts on TV and radio drawing attention to the condition and healthy ways to view and respond to it

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

Person-centred care and personal identity

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

It is crucial. With the loss of any aspect of the person's self (inhibitions, judgement, social skills, rationality etc) it becomes increasingly important to set care within a wider and longer context to take account of the person they were as well as the person they now are. There may well be times when it is difficult to weigh up present behaviour against past values but holding in mind the essence of the whole person must provide a better yardstick than an ad hoc decision made on the spur of the moment in a crisis dominated by confusion and opacity. Knowing and respecting the store the person previously placed on dignity, decorum, courtesy, kindness etc can help carers to minimise the lowering of his/her standards at least in some circumstances; eg. ensuring clothes are securely fastened to prevent them being stripped off inappropriately; using soothing techniques to prevent rages in a previously mild-mannered person.

Management of a previously bluff man given to coarse language and noisy exchanges would be different from a formerly sweetly innocent decorous old lady.

In addition if the person while mentally competent expressed a wish to avoid indignity or distress in dying, or not to be treated in case of a life-threatening illness, those wishes should be respected in living with dementia as far as possible.

The importance of good documentation and proper consultation with proxy decision makers and relatives cannot be emphasised too much.

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

Dementia can and does change a person's personality (rather than identity). But given the cause (the disease) greater credence should be given to the pre-dementia personality and wishes and preferences and values. In those circumstances where insistence on former values may be more distressing than helpful, however, it may be better for current peace of mind and comfort to accept the change as the present norm. Nevertheless this should be seen as a compromise made because of the effects of the disease NOT a change of values or lowering of standards.

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?

Radical changes can severely strain relationships and family ties particularly where the carers are linked to the person with dementia by emotional ties and they are bearing a major burden of the caretaking. Aggression, rudeness, incontinence, criticism, escaping, wandering etc, all tax reserves of patience, energy and understanding. Relentless care-giving, mopping up behind such persons can exhaust carers and further diminish their tolerances.

Relatives can also feel a profound wish to stop the person with dementia sinking any further into distress or indignity or losing more of their identity; physical death may seem preferable to a slow decline. Wishing their relative dead adds to the burden of guilt they often carry.

Family and friends may also come to see little merit in visiting or lingering with someone who doesn't recognise them or remember their visit. Why cause themselves unnecessary pain and distress for no real gain to the person with dementia? Another link with the person's past life is then lost.

There can also be an increasing burden on relatives to monitor behaviours to ensure the person with dementia is not getting into trouble with finances etc further adding to their stresses and inviting conflict.

Such radical changes can challenge the validity of previous wishes and values but it is exactly because they do, that documentation and consultation (as previously mentioned) and the appointment of welfare attorneys are such important factors in management. To dismiss these competent wishes because values appear to have changed is to negate the thinking behind such precautionary measures.

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?

At a minor level (the wish for a jam and cream doughnut rather than a healthy salad) it may be permissible to sometimes indulge the person with dementia to gratify their present wishes. At a major level (the wish not to be aggressively treated in the event of a life-threatening illness) their former competent wishes should prevail.

Where there is a potential conflict attempts should be made to minimise distress by careful management of the situation using distraction techniques etc making every effort to conform to the person's former global wishes while they had full mental capacity. But these efforts take time, skill and resources.

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

Much weight should be given to previous wishes. Then the judgement of those who know the person with dementia best, relatives and healthcare professionals, should be obtained to try to establish a consensus as to the best interests of the person with dementia. Again this takes time and skill and there may not be time or resources available to go through this procedure when crises present.

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

Quality of life is an important factor in any judgement of whether or not to give life-sustaining treatment. Dementia affects quality of life and may influence a previous decision made at a time of full capacity. However a diagnosis of dementia is only one factor in the list of considerations which lie behind effective decision making on behalf of someone else.

As mentioned above a team approach helps to ensure the best interests of the person with dementia are best represented. Prior consultations before difficult situations present and careful documentation can help to prevent spur of the moment decisions which subsequently cause conflict or guilt.

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?

Welfare attorneys appointed by the person with dementia whilst they are competent to decide, should have the power to make decisions on behalf of the person with dementia except in circumstances where health care professionals have grave concerns as to the wisdom or integrity of their intentions and/or decisions. Where there is disagreement every effort should be made to bring all concerned parties together to allow them not only to state their own opinions and rationale, but also to hear why other people have reached a different decision. A conciliatory approach and evidence of genuine concern to do the best for the person with dementia as well as full explanation of the reasons for holding a certain view can be enough to reconcile the differences. However where such measures fail to achieve consensus the case should be referred to a court or appropriate impartial ombudsman who can look at all the facts in order to provide a final binding resolution.

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 directives play a crucial role in cases of dementia. Persons who have started to show early signs of the disease should be encouraged to draw up such a directive in conjunction with relatives and professionals who have an understanding of the likely scenarios and circumstances which might present. Careful crafting the document can help to ensure the instructions represent as closely as possible the informed consent and choices of the person in readiness for those decision-making occasions

which present after full capacity is lost. However the advance directive should be one of several considerations when these situations present and should not be used as a substitute for effective communication, careful consultation and good team work.

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?

Ideally the truth should always be told. If the truth would cause distress it is preferably to evade a direct statement or employ diversionary tactics rather than tell a lie. However, the best interests of the person with dementia have to be balanced against the principle of truth-telling and sometimes a compromise may be desirable.

If a person with dementia refuses to take life-sustaining or life-enhancing medication It may be preferable to disguise medication in food or drink to ensure it is taken to preserve their good health rather than watch their health and well-being decline because a benign deception is ruled inadmissible. The continual struggle for a loved one to administer medication overtly to a person who refuses to take it can also substantially erode the good relationship between them. Deception may not be ideal but it may be the least objectionable alternative available.

Where the person with dementia is declining medication because of an on-going wish to die very careful evaluation will be needed with all concerned consulting together as to the best interests and true intentions of the person with dementia.

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?

Mostly they err on the side of caution because of the risk of negative publicity and accusations of neglect or negligence.

Freedom of action should be permitted within the boundaries of reasonable safety and where possible the person with dementia should be supported to facilitate extension of their boundaries eg, being accompanied outside on roads; being given rooms and facilities which optimise their independence, rather than being locked in or restrained or frustrated in their wish to do things. But most of these options have resource implications.

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?

Although restraint is not desirable it must sometimes be used to prevent harm to themselves or others and where there are no other better alternatives available. Ideally there should be sufficient trained staff to avoid or minimise the necessity.

In drawing attention to the issue the law raises awareness of the undesirability of restraint but it provides little guidance as to the level and nature of appropriate restraint or circumstances in which it might be used.

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?

YES!

Provide in the form of
training sessions
one to one discussion with those who support carers in their own homes
a helpline for use in crises.

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?

New technologies aren't used more extensively because of
lack of awareness about them
cost
negative connotations – eg criminal or animal tagging

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?

Creating a greater distance between the two so that the carer has space for their own needs and is not totally immersed in providing for the needs of the person with dementia
Offering adequate and ongoing support
Giving the carer permission to relinquish some of the burden of care
Providing skilled counselling

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?

Where the health or wellbeing of one is being compromised by the other

Where the health of wellbeing of the couple would be jeopardised by concentrating on only one

Where the death of one is imminent

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?

It differs between individuals and homes and families.

Individual caregivers should give sufficient information to welfare attorneys and others involved in providing care to enable them to perform their roles effectively and safely, and to make wise and appropriate decisions on behalf of the person with dementia.

A team approach is advisable to ensure best practice and safeguard against abuses of trust or confidences.

Research

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?

They should be permitted to take part if they consent now and also would have consented in their competent days provided the research a) involves no risk to them and b) benefits them or others with a similar incapacity and c) is not possible with mentally competent individuals. Their previous philosophy regarding medical research should form a central plank in determining whether or not they would wish to participate if they were able to give informed consent. Those who knew them best in their competent days - welfare attorneys, close relatives, personal care-givers - should be consulted and advised re the research in question to ensure the decision to involve them does not infringe rights or interests or values, and to minimise conflict.

Safeguards should include

A team approach involving health care professionals, welfare attorneys, significant relatives, all agreeing the person with dementia would consent if they were able to

Ensuring all the above mentioned personnel are fully appraised of the nature and purpose of the research and the implications for the person with dementia provided such knowledge does not compromise the validity of the research itself

Clear documentation of all steps in the procedure to establish that appropriate care has been taken before involving the person with dementia

Monitoring the ongoing effects of involvement in the research to ensure it does not cause undue distress or other adverse consequences

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?

Other issues

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

1. Treatments

Inequalities exist in the provision of drugs to slow the progression of the disease. How should these be resolved justly?

2. Involvement of volunteers as befrienders/buddies or carers

Some homes operate schemes using volunteers to provide more personal and focused interest and care. They are not all trained or appropriately experienced. What minimum safeguards should exist to protect persons with dementia where unpaid helpers are involved? How much confidential information should such persons be given? How much training in dementia care should be required?

3. Support

Where ethical dilemmas present how can carers – both lay and professional – access expert advice and help to enable them to resolve the situation effectively and swiftly in the best interests of the person with dementia?

4. Whistle blowing

What policies and procedures are needed to enable people who observe or experience unethical behaviours in relation to persons with dementia to expose these practices and put a stop to them without fear of reprisal for either themselves or the person with dementia?

5. Teaching

What policies and procedures should be in place to ensure that there are no breaches of the rights of persons with dementia where they are involved in teaching sessions?

6. Accommodation

Increasing numbers of persons admitted to residential homes develop dementia.

how should they be managed?

when should they be moved?

how can they be protected from the unwitting unkindness of other elderly residents who are unable to understand their difficulties?

whose interests take precedence?

FURTHER COMMENTS

The overall presentation of this report is excellent. The photographs are lovely but I believe there should be some statement about the consent of those so photographed especially if they actually have dementia!

The structure is clear and logical.

It seems odd to have a single 'Case example' on P22. Better I think to format this as in other places or create more such boxes.

Thank you for the opportunity to comment on this excellent piece of work.