

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:

Once the disease has reached a certain point the biggest impact to the CARER is becoming totally RESPONSIBLE for the person with dementia, in a way that is not usual, in any other relationship. When it is the spouse affected, there is also a creeping loneliness, as the other person one shared all life's big and small decisions with, slowly becomes unable to decide anything. The PERSON affected, at first has insight and may become depressed, as they contemplate loss of their future independence and worry of how family MAY cope. Slowly, the time frame the affected person lives in alters, and even the present is difficult to make sense of, they may become easily upset as lack of understanding increases. Ultimately, if the affected person survives to deteriorate, they can lose power of communication. To have no speech and little comprehension of language is very difficult, as is the problem of fixation on inappropriate phrases, especially if swear words! The most impact on both carer and affected person is the lack of personal DIGNITY. Ultimately, help is needed with the most basic activities ie eating and voiding waste/personal hygiene. Anti social behaviour patterns can tax patience of carers and mean the affected person is no longer able to mix in the community. Society has to meet the challenge of providing GOOD SUPPORT- both practical and timely- to the person affected and to their carer. Most people seem to feel it is appropriate to support the person in the community as long as possible, as it enhances the quality of life if continuity is maintained, brings increased stimulation to the affected person (when care is tailored to their needs),and allows the pre- illness relationships to carry on as long as possible. Support will obviously vary according to individual circumstance. I am aware how reluctant some affected persons and/or carers are to allow "strangers" into their world. This may be because of fear of being judged, or losing face or because they feel the issues are theirs alone eg vows taken for "better or worse" . Early on in the diagnosis support may be a listening ear, some one who has understanding of the condition, and of the circumstances of the individual. Someone who is not a family member, who may not need "protecting" from the worst of a situation. Sooner than the affected person and the carers think they may benefit from more formal advise re finance- taking advise on power of attorney, State benefits -- daycare services, sitting services, support groups and advise re some medication intervention. I have found that a lot of patience is needed to persuade individuals to try out certain areas first ,that the carers in particular, need a lot of reassurance that their loved one will be safe and that their own role is not going to be diminished ,by the help of others. The current challenge is

to provide the good quality, flexible service that individuals need SWIFTLY .In my experience, as the daughter of an affected mum and a caring dad ,and (as a GP for 20 years),is that , BY THE TIME HELP IS ASKED FOR IT IS MORE THAN NECESSARY . At this point if care cannot be provided, demoralisation of all concerned is a real problem ,making the affected person and the carer at risk. As the person affected declines, or the caring situation is too difficult, periods of good Respite care are invaluable .Planning this a head is helpful and having chance to choose where the affected person will stay helps. In my families experience, respite is difficult to get, once difficulties in behaviour arise. Specialist units who can give good care are a good distance from our home -- but we use them to keep the situation afloat. Flexible care, which can be tailored to the affected persons and carers needs, is the key to successful outcomes. Patience and understanding to help plan the care and involve the individuals in the choices , as much as possible, helps the carer deal with inevitable guilt ,when they reach a point when they cannot give the care needed any longer. I have found some individuals continue to care in the community beyond when the person affected could actually benefit from the freedom of residential care. One example can be because of the benefit of a larger building to move around in ,with varying faces and characters to interact with .It is important to explore with carers how the needs of the affected person will change over time - trying to reassure that the quality of well run specialist units can deliver what is needed.

Q2

ANSWER:

The issue of medication is an ethical question in that the affected person cannot consent to taking medication but needs it. For example in the case of preexisting problems like for the treatment of reflux. Also antidepressants, as without that tearful episodes can become very frequent and distressing (so treatment does relieve suffering). There is often the issue of sedation to help sleep. The latter is perhaps the reason for most debate, but sedation means both carer and affected person sleeps. There are issues of benefit to both, the affected person being really unhappy if not slept and subject to falls due to lack of alertness. The balance of medication is important as over sedation could make new problems of unsteadiness arise -- hence the need for carer to be closely involved in monitoring changes and fully aware of possible side effects of medication given. (In my experience some care home situations those that administer meds understand far less than the elderly spouse caring at home !) Respite care can prove ethical dilemma in that the affected person would far more wish to stay at home but the carer needs a break. We make a choice and persuade the affected person to go into respite to preserve the long term wishes of the affected person at that point, at expense of short term wish. My mother and I had long discussions about what may happen as she became worse and she made it clear to me that I and my father were to get all the help we could- ""choose the best care and then get on with your lives "" was her instruction on many occasions over time, made in the light of her own experiences, having cared for her own

Mum in the past. For me this helped, emotionally and highlighted the need for discussion early in illness. Discussions served to ease possible burdens for me as carer in the future and to enable me to respect the pre-existing wishes of the affected person, as far as possible. My comment in conversations with mum, was always to say that I could not promise anything, but would try to make the best choices at any given time. The fact that we discussed my possible dilemma of not being able to carry out her wishes is important too. Mum understood why I could not "promise" because the future choices were not known to either of us. Appropriate, long term place of care choices, can prove ethically difficult as the affected person often cannot select to go. It can be, also, that the carer may wish to keep the person at home so that they themselves are not lonely, or out of a sense of duty, or to have a role, when the person affected has become very challenging in the home environs. At this point the affected person has more negative experiences thru carers trying to protect them " " stop that " " you cant go out " " don't do that " " put that down " , than if in residential care. Whose choice is it ethically, where the care takes place then?

Q3

ANSWER:

I don't have much experience about this -as a GP I see many different families struggle with the situation and have not seen many cultural differences. I know a small Asian population and also migrants from Ukraine and Italy -- I do not feel their cultural differences affect the outcome more than the individual relationship quality within the families. There are real issues with the mobility of families as place of care and support problems arise sooner for the affected person, if there is no extended family or spouse.

Q4

ANSWER:

CAN ONLY IMAGINE PROBLEMS WHEN TRYING TO GIVE CARE AND NOT AWARE OF SOCIAL TABOOS. AWARENESS of individual culture must be part of tailoring care to the individual - resources should be made available to facilitate this, as not always possible to gain all info needed from immediate family

Q5

ANSWER:

Any medication that would slow down the processes of dementia would be welcome, as would better understanding of the place of any medication for certain difficult behaviours. Agitation is difficult to deal with, as a carer, in altering environs, but causes real distress to the affected person too. I see my mother unable to sit still from 8 am till 7/or 8 pm unless she is being fed, she is 72 and often very tired but cannot allow herself to sit for more than 5 minutes.

If given even mild medication she is too sedated to have any quality of life. We try to distract her, with attempts at conversation but she has lost the ability of speech, so that is ineffective now. Mum can sit in car for a while, but now easily becomes distressed at a journey of more than 10 minutes. She would be more content if medication could let the "" drive to move "" ease off!!

Q6

ANSWER:

When there are treatments available I do think discussion re memory loss early is useful. If a person is to prepare for the best outcome, even if no treatment is possible, discussions with family can help ascertain the person's hopes for the future. A society where people with early problems are aware and can share their experiences also reduces taboos a little. We know not every one declines at the same rate, and so in the community, then can see individuals active in some aspects of life whilst needing support in others. If the diagnosis is not shared until the affected person loses insight, they are denied any active part in planning. Legal provision is made more difficult if power of attorney etc not planned. Secondary distress, of depression, for example can be eased if the diagnosis is made and treatment is accepted for depression. An individual affected can decide, early in illness to affect the environment without worsening the memory loss. For example an affected person may choose to move nearer to family or into sheltered accommodation or into smaller accommodation, so allowing their independence to continue longer. Leaving a choice like that later can even worsen the symptoms of confusion in particular as if moved residence nowhere is familiar and independence may be lost sooner.

Q7

ANSWER:

Society has a fear of Dementia because of lack of understanding. However I am aware over recent years of the increase in numbers of affected persons, meaning that families often have some experience of the condition or indeed people work in the caring sector themselves. Personally, when I am out with my mum and apologise or attempt to explain some slightly quirky behaviour, many people are very understanding and make allowances, or offer to help. I am not taking her out as a crusade to illustrate care in the community; we are just out together as mum and daughter. My mother is very friendly and loves to be out in a group of people. This is how she has always been, and I feel she still enjoys "company". However there are risks, and I am aware that when we are out she could be exposed to ridicule (her pre-illness self could be embarrassed by her attempts to talk to strangers)- but I rationalise that away by the pleasure she has now by being with people.

Question

8

ANSWER:

Sadly stigma is almost ubiquitous in the realm of dementia .Despite the number of individuals affected by dementia there is little funding for research and little spent per head on care and support. As families with dementia affected individuals know, it is very hard to get help from agencies, as the elderly with dementia seem to be low on priority lists for help . There seems to be little motivation to put right care homes that fail, in comparison to any similar situations with say, children, being badly cared for. Rightly, outcries occur, against any children's care failure, but not so for the elderly with dementia. Persons who work in the care giving services are not expected to have particular training and are not valued in their role. In my family we have seen the difference experienced and well trained care giving can make. Risks are less to the affected person and the carer is not stressed by care failure, or double checking every situation .Well trained carers keep their motivation, stay in post, and will share their knowledge with the wider community. Those previous known by affected persons ,who could give support to the affected person and the carer, often fear the presentation /affects of the dementia and so decrease or cease contact.

Q9

ANSWER:

Certainly we should encourage those with early dementia to be active in their community as long as is possible. That way the individual can be effective in de-stigmatizing the condition as the community can see certain aspects of dementia can be lived with. Many patients retain insight for a long time and could also be helpful in letting the care giving service know what would help, taking an active role in shaping services. Many persons are affected in different areas at different rates and I have known some persons retain ability .In particular with music, when reading and cooking, for example are no longer possible . Many, for some time after diagnosis, can shop, attend worship, attend coffee mornings, hairdressers etc with help, or observations from others. Being able to attend day centre and specialist centres near to home helps the carer with ease of access, may mean the locality is familiar to the affected person and that others working or attending may be known to them. Later in the illness community living can be less possible because of the physical risk of the environs, and unpredictable behaviour of the affected person towards others.

Q10

ANSWER:

This idea seems useful as it emphasises firstly that there is a person involved and not a ""sufferer ""or ""patient "" . This also helps all involved accept that no two people affected are alike, and as such, their needs do require individual tailoring to obtain the best care outcomes. Patient centered care dose imply also, input from the affected person, by previous information given or written for others or indeed current information they may be able to provide.

Q11

ANSWER:

The dementia does change a person's personality to a greater or lesser degree but their identity remains. Many individuals retain awareness of their name and often role even when many other awareness has been lost. An individual always has the history and family connections of their identity. Sadly the aspects of the personality that are accentuated or lost can subtly change or completely change how the person behaves. This makes previous relationships strained, sometimes to breaking point.

Q12

ANSWER:

Moods that are very labile can upset both the affected person and those that care. Depression and tearfulness swing to giggling and maybe, aggression can be challenging. There may be reasons for the reactions and a carer that knows the affected person well may be able to reassure them. Other times the emotion cycles are part of the illness presentation itself, and not easy to manage in any environs. The affected person can be in direct conflict with their own previous wishes - eg stating a desire to always be at home early in the illness but then becoming distressed, by not recognising the home and wishing to leave - paradoxically the affected person can find it easier to relax in residential care where they can accept an explanation of staying for a short while, or feel safe with people wearing nurses/carers uniform. More difficult is the issue of affected person wanting to stay at home when no longer safe, because of wandering putting the person at risk, or if the carer is suddenly taken ill etc. Family ties can be damaged as the person affected becomes "awkward" or "argumentative" before a true diagnosis is made and even sometimes lost altogether. My mother lost touch with a couple of friends as they were offended when she made arrangements to meet and then repeatedly forgot. I only discovered later when I met the friends, by chance, a year or so later and could explain what had gone on.

Q14

ANSWER:

These situations will always pose a dilemma and should again produce group input if possible. I have as a GP met situations where caring relatives have really wished an affected person to accept residential care but the affected person is still able to accept a degree of responsibility. We discuss their term ""ACCEPTABLE"" risk- trying to find if the potential risks are as great as the real risks eg of fall or being burgled. When often the family and support staff GP etc think it through we agree to respect the affected person's wishes and try to increase support, with the aim being to limit risk if it can't be removed. We often agree a time scale to re-visit the choices too - that is, nothing is decided for ever, circumstances are recognised to change. I have been involved with

advocacy one occasion and that helped focus family members minds on the affected persons limited but existing ability to decide an issue re place of care .

Q15

ANSWER:

The person affected must be given treatment if quality of life can be given. Not ethical to withhold treatment eg for breast cancer and see person suffer .A judgement need to be made by clinician and carers whether the affected person can cope with the operation /treatment offered. May be treatment can be modified to match what person can cope with , but that occurs in patients with co -morbidity and no dementia already. Respecting advance directive not to resuscitate is possible without having to withhold treatment that can affect QUALITY of life. Many affected persons will lose appetite or ability to eat--supplementation can help maintain their weight and enhance quality of life but artificial feeds can tie patient to periods of immobility and provide routes of infection. I recognise this as an area for ethical debate however.

Q13

ANSWER:

In dementia ,the past present and future are often in a state of flux ,and so trying to balance best interest for the person shorter term .Longer term planning and considering the pre illness choices is often very difficult. Depending on how risky the choices are it is helpful to recall the persons prior wishes, but each case can only be decided when as much information regarding the situation and carers input should be considered. If the carers needs, and affected persons needs conflict, perhaps choices should be made by Advocates, with input from family and clinicians, carers and support workers. That means a group choice is made. As a GP I am aware of the time needed to explain as much as possible about choices and consequences. One patient with dementia, unable to decide treatment outcomes herself with vulval cancer had support of her family, who felt she would be distressed by treatment. However the treatment would have been short, done as an outpatient and probably spared her horrid death from ulceration of the lesion thru to bowel. Had more time explaining possible outcomes gone on, the treatment could have improved the quality of her life considerably.

Q16

ANSWER:

May well be a growing need for this to be organised and accepted. I think it would need well resourcing as often choices have to be made swiftly or else, by default, the affected person can suffer by no choice being made. Health professionals should be able to make the case to an attorney as to why any pathway is recommended. My only fear is the slow pace at which consultation with the law can move, has potential for adverse outcome. If disputes do occur

then there must be a form of ombudsmen? Perhaps a small panel of three to help decide-- but practically only for major choices.

Q17

ANSWER:

These can be helpful but often when I have read them as a GP they cannot be specific enough to help in a particular situation. For example, a patient may stress -no artificial feeding but, a medical problem could occur where this need is temporary, completely reversible. How can we know the persons wishes then? In principle however I feel that discussions are helpful, if held with family or persons who will in law be asked to decide. Then the directive can have more meaning.

Q18

ANSWER:

Do not have any direct experience with these legislations, but as a GP would have expected to come across them if they were of use!!

Q19

ANSWER:

YES, I feel it is as once the affected person has lost insight repeatedly telling them bad news eg "your husband is dead "or that "the children don't live here anymore" just upsets them. An explanation such as " they are not here right now " is the truth but not the whole truth and may avoid agitation and distress Managing dementia is all about having to be flexible and not dogmatic .Insisting on correcting a person fuels mistrust - reassurance in terms of reference the person can follow, requires an understanding of the illness as it affects the individual. This approach gives much better results. Avoiding confrontation helps in giving good care. When a person affected with dementia refuses to accept the need eg to take their coat off, if we" fight" it is not helpful. Leaving the process until 5 mins later, and using a reason for example " its hot in here wont you be more comfortable with that thick coat off??" can give a different response. If not try a different idea 5 mins later again ,and so on . It is not good to use lies however, as the affected person can surprise you by what they retain and then perseveration occurs!! "You told me i could go home tomorrow - well??" . I accept there is room for debate.

Q20

ANSWER:

Generally, in my experience as a carer and as a GP ,carers over estimate risk. When you accept responsibility for another person you tend to over compensate, seeing adverse events or possibilities everywhere. I have had to tell myself that stopping my mother from going out with carers or me would mean

she is safer, from less falls or ridicule or even infections yes -but what sort of quality of life would she have then with no variety of stimulation ,no new faces, no meeting people, enjoying sunshine etc . I constantly juggle with tolerating uncertainty and assessing degrees of acceptable risk, in supervising my mothers care. Also, in considering how much stress my father can cope with, in his essential caring role, the same types of concepts help.

Q21

ANSWER:

Physical restraint, like tying a person to a chair , is never acceptable. Sedation, if managed well ,can be a component of enabling good care to continue - context is everything. Persuading some one to get in the car to go to day care, by saying they are going elsewhere is ok ,but not physically handling them into a car or bus. There are ways of dealing with a person if you take the time- and that is why care situations need valuable training and remuneration that fits the skills needed. Regulations are there to check out residential care, but in my experience the will to carry out good care comes from understanding and organisation of the care home- investing in staff training and conditions of work .The law doesn't seem to motivate ,and in may area , failing homes continue to fail despite initiatives pass, carers slip back to original ways .

Q22

ANSWER:

I feel that managers of care homes and support workers need such training and that special attention is given to patient- centred care .Understanding the process of dementia itself and how a carer can help give care to an affected person can help carers self esteem . Family members, who care, also benefit from support groups where ethical issues can be discussed in the abstract, and prepare them for dilemmas they have not yet reached. Providing support and on going training in care homes is vital, making available support and supportive "training " to family carers can be sensitively done by workers fro example from Alzheimer society .

Q23

ANSWER:

Lack of acceptability of tracking is perhaps because it is impersonal and their use reminds us of criminals. Care to affected persons is multi dimensional- and if technologies are useful they are welcomed, but dementia seems an area where a person to person approach is needed. A person affected by dementia will not be able to understand the need for a bracelet or anklet .Knowing some one has left a building ,and is off down the main road is not a lot of use if they are then knocked down - we need people to supervise in a timely fashion. However if trackers could be in strips within clothing/shoes etc they could help find lost or

wandering individuals.

Q24

ANSWER:

We in the UK have an ethos of caring for the ill person ,regardless of what disease, or a persons status or means. Ethically , the state then, cannot disown a significant part of the population- dementia is an illness and as such warrants more investment, in research , carer training ,support in the home , support to families (financial and practical),and access on a swifter basis to social service provision. Means should not be as important as they are now - it is very unfair for a person to have worked and saved hard to see all that would have been for retirement , to go on care bills . The couple loose their retirement to the illness and the money to caring, when other less frugal persons get all from state.

Q25

ANSWER:

This is an issue that requires advocacy if wider family cannot agree on choices to be made. Compromises have to be made when a person is ill with other conditions not affecting memory and persons may have to be persuaded to accept less than their ideal place of care for example . Having involvement of all agencies an help .

Q26

ANSWER:

Someone with training can help carers and families see choices - if real dilemmas exist perhaps advocacy can be used. It would seem foolish to place too much responsibility on one individual, but the person with dementia is a vulnerable adult. As such protection from social care professionals may be needed.

Q27

ANSWER:

Not sure can say - we have to look at each case. If the person who is caring is also affected by dementia then such judgements need to be made .The absence of family members and perhaps over relying on "friend" influence could need such intervention.

Q28

ANSWER:

OFTEN THE INFORMATION IS ADEQUATELY SHARED , as family member has to attend appointments - as the affected person cannot organise care themselves .It is always important to keep information in context - medical

information ,if not disclosed ,can mean affected person would suffer . Seeing families together is not always easy, as future planning may require the family to know more than the affected person can take in. However, non relevant past information ,should be respected not disclosed . Often stating the abilities of an affected person as well as their inabilities can be helpful to families and carers. Context is always important ,and if any information cant be given in front of an affected person we should perhaps consider whether advocacy or ultimately , power of attorney be sought??

Q29

ANSWER:

TRYING TO HALT THE PROGRESSION. Also help with meds for agitation and behavioural issues could benefit, as currently so easy to over medicate. Yet agitation etc is distressing to the individual, certainly even being aggressive 24 hours a day cannot be a nice feeling to live with as the affected person never mind the carer or spouse. Looking for prevention and/ or cure is worthwhile, but slowing progression would buy a lot of quality time ,as would helping distressing associated symptoms .

Q30

ANSWER:

Ideally consent should be obtained .Asking patients at the onset of illness could be acceptable. Ultimately if the only way forward is to ask for carers to volunteer, then third parties should be consulted to be sure possible risk are adequately explained to relatives. Because of conversations I have had with my mother, I know she would want to take part in anything that may prevent another person being affected as she is. She would be quite cross to think that she could not take part , because she could no longer consent herself. The issue would be how others may benefit from the knowledge gained by trials, not if she could benefit herself.

Question

31

ANSWER:

I think if trials were needed with affected persons, new decisions need to be made here . The process of dementia is important and we need to respect the individual, but collecting consent from relatives should be made possible . Alternatively ,it means consenting patients early in illness ,(when Memory assessment tools could show they have insight).In this way the potential to enter a trial of some sort , at some point could be explained to the affected person and their next of kin. This could operate like "a donor card "type of idea ,the person has given consent in advance. Would society and the law feel this is enough?

Q32

ANSWER:

Is it ethical to withhold treatment because it is expensive? Is it ethical to tell families the affected person can have help with personal care, but they are low priority, there is no carer available- don't we have the duty to provide ? Is it ethical to make affected persons pay for care once provided, when if they are ill- that is an NHS role ?