

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.

Chreanne Montgomery-Smith

QUESTIONS ANSWERED:

Q1

ANSWER:

Loss of confidence, self-esteem and then resultant depression seem to me as disabling as the brain damage if not more so. (The Nun's Study anomalies point to more capacity than the damage can account for.) This is often caused more by lack of early intervention due to the fear and stigma of this illness preventing consultation with the GP. Counselling, neuro-rehabilitation, strategies for externalising memory and training to use techniques and technologies which minimise disability are all available to people with head injury but not to those with progressive memory loss. Enabling people with dementia to stay in charge as long as possible should be the aim. A U3A for people with memory problems would give people some dignified way to approach these therapeutic aims. Knowing that schemes like this exist would encourage earlier diagnosis. The loss of a self-help approach seems to me to result in social withdrawal, and increased passivity. Drugs may be helpful to people with dementia but are seen as a magic bullet. They do not give the best result in isolation. Training/counselling/rehab should accompany drugs to use extra capacity to increase activities of daily living and quality of life. These must be given in an enjoyable way to reduce the fear of failure which may be strongly ingrained by the time of diagnosis.

Q2

ANSWER:

There are many ethical questions but here are two: the lack of consistent help for highly intelligent people who have experienced significant loss of capacity but who pass the MMSE with ease the lack of consistent help for those diagnosed as MCI

Q3

ANSWER:

In my experience with one Caribbean family- some family members accused the carer of witchcraft bringing dementia to her husband. This caused reduced family support. Literacy problems have caused many disputes with social services. Social Care/Direct payments/respite arrangements are all adversely affected by low socio-economic status, literacy and ethnicity. Advocacy is needed for families.

Q6

ANSWER:

I believe that diagnosis should occur at the earliest possible moment and that programmes of neuro-rehab, memory training (externalising memory), counselling be available to help people make adjustments to maximise their capacities and prevent serious depression. These should be available to MCI patients as well to encourage pro-activity for health. These need to be fun, life enhancing and delivered in group settings to encourage new friendships.

Q7**ANSWER:**

Negative campaigning has continued to stigmatise people. Not enough is done to help people stay competent longer. Not enough is done to illustrate people with dementia enjoying a good life. Good care homes never feature in the news so people continue to be bombarded with distressing images of poor care which creates more fear and despair. Leading by good example might help remove some of this fear. There is more sympathy in many quarters than there was ten years ago but shocking rejection of people with dementia in others suggesting euthanasia!

Q8**ANSWER:**

The stigmatizing view that people have no capacity for growth, new learning or creativity damns people with dementia to boredom, inactivity, passivity and depression. When one skill is impaired it is often assumed that any task involving it is impossible whereas providing external cues to memory can allow independence much longer. Problem solving over activities of daily living may help overcome difficulties and maintain self-esteem which helps maintain competency.

Q**9****ANSWER:**

Yes if they wish. Our West Berkshire branch of the Alzheimer's Society has worked very hard over the last 5 years to make social therapeutic activities available to people with dementia and carers. These are like U3A classes but more supported. We developed "Singing for the Brain" in 2003 having observed how well preserved memory for song is in the brains of even very late stage people with dementia. We felt it was a way to restore confidence, self-esteem and some communication skills. We have gone on to develop "Gardening for the Brain" in partnership with Thrive and "Gentle Exercise" to help prevent falls and preserve motor skills with some moving yogic meditation. We try to involve people with dementia and carers in planning and certainly in evaluating these group activities. We recognise that not all people with dementia wish to join with others and try to support them respecting their wishes collaborating with

other voluntary and statutory organisations. Our aims in these activities are listed below: To lift or prevent depression through the use of elements which will surprise , reassure, support , inspire and mediate reframing a negative life viewpoint into a positive one To become something G Ps can recommend to patients as they do exercise and thus help them to feel diagnosis is worth doing To help families with dementia "come out" and feel part of society where they have a right to artistic and social stimulation To encourage carers and people with dementia to be pro-active in looking after themselves, to network with others in the same boat who might exchange help To give families a view of themselves as managers of their life not victims of fate.

Q10

ANSWER:

Tom Kitwood's ideas are wonderful but are not often realised. Care homes put them in their brochures but not much into their practice. The need for people to be able to rehearse themselves with good life histories and cultural references specific to their lives is vital to well-being. Time spent in early dementia can save identity loss later. The impact of stigma on personhood is huge so counselling, training in company with others in the same boat for persons with dementia in coping skills and externalising memory for reference, and in preserving relationships is essential. Training in spiritual practises (Yoga,Tai Chi, Art of Living Breathing, Singing) combined with exercise can bring the bloom back to people dulled by loss of confidence and depression. The use of buddying systems such as at U of Colorado with exercise can help families so much more than clinical rehabilitation. Breadth of opportunities offered to all people with neuro conditions needs to be offered to help people live well in good heart.

Q11

ANSWER:

It is difficult to separate the changes caused by various bits of damage to the brain with those caused by malignant social psychology either pre or post diagnosis. In families where confidence and good communication is maintained this does not happen so much - there are fewer essential changes. Where relationships are poor predating dementia there is more likely to be difficulties. In truth it varies a lot, but we are at a very early stage of understanding how to help people live the best possible life.

Q12

ANSWER:

lack of understanding of the causes of moodchanges/behaviour can blight relationships. Revulsion at these rather than problem solving the reasons behind them can destroy or weaken ties. Role reversals need not be total if understanding and respect are promoted by good education. Counselling and social therapeutic activities to share pleasures can help maintain family ties.

Sometimes these ties are very unhappy before dementia strikes and many problems arise later rooted in that unhappiness. Frustration at loss of capacity is a common factor in causing aggression. Learning to diffuse this is helpful on carer courses and learning how to deal with this is part of courses and counselling for people with dementia.

Q13

ANSWER:

This is an extremely fraught area as when one is fit and well in late middle age people often say "don't let me suffer the indignity of dementia or long term conditions where I cannot communicate". This reflects the stigma of the illness and the poor management of it. The lack of work on preserving communication skills in dementia would be shameful in head injury or learning disability and the greatest impetus to people saying on end of life directives "do not resuscitate if demented". It has been my experience with a few people that they refuse all treatment and help because they feel they must hasten their end so as not to be a burden. The difficult problems in palliative care are related to the fear that pain will be undetected and untreated due to poor communication. All these enter into people's fears and determine past wishes but current circumstances may not prove so terrible and so people may not want their previous wishes honoured because they do want to live.

Q14

ANSWER:

Without a huge and well trained advocacy service independent of health and social care, it is difficult to see how to manage this balance. Each set of circumstances will have unique features and a unique point of balance between harm and benefit.

Q15

ANSWER:

It already affects those who also have cancer care and lots of other conditions - cataracts, hearing aids are particularly vital to quality of life in Dementia but often need specialist diagnosis which is not readily available. Life threatening emergencies are usually responded to but things with gradual onset are much less vigorously treated in those with dementia. Pain management is particularly problematic in those with poor communication skills.

Q19

ANSWER:

I know there are many instances when telling lies is easier for carers in the short term but the undermining of trust can have very serious consequences. It is better to respond truthfully to the feeling expressed. "I want my father"

according to David Sheard means "I feel unjustly treated and want an advocate". Responding with "your father is dead" creates grief and does not address the reason for the request. This could lead to unnecessary misery for all. "What's the matter, I know your father would help if he were here?" might be a more appropriate response with time spent teasing out the difficulty. It is not easy but planning ahead when there is a need to explain something difficult. Using a tape recorder so that the explanation can be repeated when the explainer is gone. Using calendars to show when someone will return....

Q20

ANSWER:

The risks need discussion with the person and respect given to their point of view. Every effort should be made to err on the side of independence but help must be given to prevent exploitation. The targeting by criminals of older people to defraud them needs to be rooted out more vigorously. Perhaps Citizens Advice Bureaus/U3A classes could be involved in giving financial training to older peoples groups to help them find ways to protect themselves from exploitation. Incarceration in wards and care homes -preventing freedom of movement and the completion of ordinary tasks is in no ones best interest in the long term. It creates rebellion/hostility or passivity/depression/withdrawal. Using staff shortages as an excuse is untenable. People need to be accompanied to accomplish their purposes if they are frail. Fear, anxiety-lack of meaningful occupation and reassurance lead people to want to "leave" and walk out their emotions. Vital that this is planned for when it arises. Life story work can provide clues to the need for occupation at certain times of day. There are more risks in ignoring this . Protection of people can become an end in itself which is disrespectful. It is not living.

Q21

ANSWER:

Protecting others may necessitate manipulating the situation so that a person is no longer a threat but provocation with restraint is not usually the best solution. Prevention by engagement should be the first way of looking at problems. The 2nd example is very much more common in the community and sometimes arises through lack of imagination in overcoming fears of the car, fears of being outside of familiar territory,fear of abandonment, pain on movement, lethargy relating to depression etc.Baulking is also about rushing a person, not giving reassurance and not preparing far enough in advance for the outing. It would be helpful to be able to give carers strategies for overcoming this as allowing fears to govern life leads to understimulation and more fear. We all know of personal experiences when we judged ourselves too tired for something but having dragged oneself there, have enjoyed it immensely. This kind of "bullying" can go too far if fears are terrors so it is wonderful if really skilled people can be involved in persuading the person and training family members to use different techniques. The 3rd example is for the convenience of staff at poorly managed

homes who do not walk with people or give them meaningful occupation. Excuse of fears of falls must be addressed by gentle exercise classes daily to help people stay fit and maintain their balance. 4th example is better addressed with aroma therapy and gentle conversation which will not cause falls or strokes. Drugs store trouble for the future. Controlling "difficult behaviour" should be on the Merevale House model of offering respect and unpicking the reasons for what happened. Meaningful occupation can be a very powerful way of avoiding difficulties. People with dementia can learn new things, can be creative and have pride in accomplishment if given a chance. Getting this right in care homes can reduce staff turnover as they can be involved in enjoyable activities with people and love their work. In Extremis- not all circumstances can be foreseen and if extreme danger to other person or to self is present then minimal, very short-term restraint might be necessary until other attempts at ameliorating the situation may start. Training must be given to persons with dementia, and all who care to develop strategies which deal with frustration, fears, boredom depression and anxieties which contribute to causing difficult situations.

Q22

ANSWER:

Yes but it should be part of good all round dementia education provided so that responding to people with dementia could be more genuinely healthy and helpful. Counselling services offered to both People with dementia and carers would help greatly too by diffusing the buildup of resentments and frustrations.

Q23

ANSWER:

Consulting with people with dementia about what they want and training them to use technologies is a wonderful way forward. Externalising memory using computers, dictaphones, safety devices all should be part of the courses offered to people on diagnosis. Everyone needs to know what is available and that this is an expanding field. It all can be part of encouraging a problem solving approach to managing memory loss. Knowing that there are devices which help you stay independent is important for psychological armour against passivity and depression. People at an early stage in their illness could discuss and decide on any consent issues. Intermediate care/ reenablement/OT teams can teach people to use devices to maintain skills of daily living and thus maintain dignity and independence. Tagging that helps people feel secure to go out and take fresh air and exercise for longer is a good thing. My only concern is that Telemedicine and some technologies may be used as a substitute for talking to people or visiting making them lonelier than ever.

Q24

ANSWER:

DirectPayment/ individualised budgets can provide creative solutions to almost insuperable problems but the management of them is only suited to middle class accountants in my experience with Reading Borough Council. The language and communication skills of support staff are not always suitable. Carers are blamed and threatened for the mistakes of others and suffer great stress. Certain valuable services may be dropped unless carers band together to commission them in the future. Carers duties often leave them with little initiative. Opportunities for empowerment of carers and people with dementia must be devised so that supported self-help is encouraged. Society as a whole needs help in choosing to be well. Education from an early age to help even the poorest eat well. But at the stage when people cannot choose ie when they are ill the best provision should be made to help them help themselves. There is no expert patient programme clearly organised for dementia. Education schemes to keep MCI people able and persons with dementia skilled in managing memory loss should be much more mainstream. The state needs to look to existing resources which are underused like village halls, church halls to build community health and well-being. Helping everyone to be the best they can be and creating a sense of community like in New Zealand in the Great Depression where community singing was compulsory in every village hall weekly to hearten people in tough times. The state needs to promote healthy empowerment and community building to people with long term health conditions can make decisions about what they would like and commission them. Late diagnosis of dementia robs people of self-belief and encourages passivity which prevents self help. Fairness in charging for care, easy access to diagnosis/treatment, development of policies to preserve mental strength are vital in preventing costs spiraling.

Q25

ANSWER:

So much hinges on relationships predating dementia. Those with good relationships have a better chance of success provided timely support and education are provided. Flexible care allowing younger carers to maintain jobs and to reduce the risk of later poverty is essential. Skillful home befriending schemes which lead to day care located within lively residential care settings would make for more successful respite stays as persons with dementia could have familiarity with place and staff and continuity of routine. Day care should be preceded by short social therapeutic activities in the community to build confidence

Q26

ANSWER:

Independent advocacy might help here. There are so many conflicting factors which make decisions difficult for example where one partner is much older than the other for example or where co-dependency is very strong. Sometimes extraordinary efforts to support people at home are the best solution for both.

Sometimes experiments have to be made to see if a solution will suit with a recognition that after an agreed trial period another solution could be sought if the first is inadequate. There is a need for more flexible arrangements like the wonderful Methodist home in Swindon which takes couples with widely differing needs and one in Tadly Hants which is well thought out (religious) but both take people from the environment where friends can pop in. if such places existed in each locality people would have more sensible choice.

Q27

ANSWER:

Where separate solutions might lead to desperate anxiety and/or deterioration in health it is important to think creatively of the couple as a team who are best able to support each other emotionally and facilitate other care around that. see previous question

Q28

ANSWER:

This is difficult because each family is different and professionals seldom have an in depth understanding of the family dynamics. It is important at diagnosis or shortly thereafter to discuss this with the person giving them clear written list of benefits and drawbacks of whether is best to disclose or not. A booklet of examples would be helpful. Then the person can make an informed decision according to their circumstances. Written instructions can then be in the notes. Obviously this is dependent on reducing stigma and then getting earlier diagnoses and the sensitivity of the diagnosis. In Australia there are (compulsory?) facilitated family meetings where all are encouraged to pledge support of some kind to the person diagnosed with education in dementia offered. On the other hand there are cases where stigma causes denial in a person with dementia and much help could be lost without the Dr having a right to exercise his/her judgement about what is best for their patient. Health information to a main carer should be given to ensure best care.

Q29

ANSWER:

In the short term, measures that delay onset of worst symptoms -like managing diabetes are necessary. Studying the benefits of social therapeutic activities/life style interventions on delaying adverse events and promoting self-esteem, reducing depression. Using neuro rehab in social settings full of fun and laughter. Less side effects than drugs. Care needs to be enriched -after all it works for rats!! In the long term cure/prevention is vital. Understanding the mechanisms of damage and reversing/containing damage. Establishing basal referents to normal ageing based on executive function in activities of daily living rather than MMSE would allow easier measures of efficacy without

expensive scans.

Q30

ANSWER:

Testing for safety must be done with informed consent either with prior written consent at an early point in the dementia or in a taped interview in which things are carefully and fairly explained. Efficacy trials after safety is established might be more leniently approached with families able to give consent. The use of cross-over designed studies reduces some of the ethical problems. Persons with dementia and those with long term conditions generally benefit from being involved in research from the extra TLC, social interaction and sense of purpose. Medically, there is extra advice, and sometimes reconsidered diagnoses. Perhaps advocates can be appointed for those who have no welfare attorneys to ensure risk of harm is minimal. As in the immunisation trial there are may be unforeseen adverse results especially in severely compromised individuals for whom research offers the only hope.

Q31

ANSWER:

The process is lengthy, complex and does delay research into non-invasive or rehabilitative care methods which are much less likely to cause harm than those which involve drugs etc. Perhaps there could be fast track procedures through bureaucracy reflecting lower risk.

Q32

ANSWER:

Making dementia part of the mainstream of health and education would reduce stigma and encourage people to help each other as they age which gives older people much more dignity than allowing deterioration to the extent that social care is needed. Wider issues of being useful in older age and maintaining healthy social/physical/mental/cognitive activity levels should be tackled by extending existing resources (Life Long Learning) and helping with transport. The U3A model of self stimulation combined with local village hall activities could help more people be less passive about health and about their value to the community. Exercise classes nearer where people live and prescribed on the NHS. Helping people with dementia learn to use computers to allow meaningful conversation at their own pace, developing makaton or other communication systems (tape recording, dictaphones, personal gps and other memory devices) to ensure communication and freedom of movement can continue as long as possible. Making Memory Enablement part of mainstream Education and Exercise regimes so that everyone can access systems which help preserve independence. Best practice from round the world needs to be promulgated widely to stop costs spiraling which could cause resentment across generations.

