

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.

Question 1

ANSWER:

There are so many elements that have an impact on the person with dementia and their families and carers. I would suggest the following are the main areas; 1. Discrimination - the PWD is viewed by society and sometimes from within the family unit as 'less of a person' and there can be people/services/members of society who will exclude the PWD because of this. 2. Change of role - The PWD may lose skills and others may step in to compensate, it is very difficult to get the right balance between 'doing with' and 'doing for'. 3. Loss of self - The PWD may become a condition and diagnosis rather than an individual (Malignant social psychology is very evident in dementia). For the PWD it is important for a person centered approach to supporting them with their condition and for the PWD to be involved in early diagnosis and early interventions/Care mapping to ensure that through the progression of the condition their wishes and preferences are taken into account. This would also aid carer's and families to feel included and not to feel worried about what the 'right thing to do' is.

Question 2

ANSWER:

Decision making in care, my experience has been that families will often make decisions about care based on their own needs rather than that of the person being cared for, also, there may be family members that have not had a relationship with the PWD but feel they should be the one to make decisions. This is ethically challenging because in the eyes of the law the next of kin has rights but this may not result in the best decisions being made for the PWD. Other ethical problems I have experienced relate to the covert use of medication, withholding information from the PWD, having to conduct mental health assessments but at the request of family members not being able to tell the PWD what they are for, also family members refusing for a mental health assessment to take place (due to stigma, denial of problems etc). Other problems encountered include removing people from their own homes (following risk, capacity and mental health assessment) to go into residential care at request of family members.

Question 3

ANSWER:

It is my understanding that certain cultural groups do not have a word in their language to describe mental illness or dementia and because of this group of people require specialist intervention in the early stages to have education regarding the concept of mental illness and dementia before any further intervention can occur. There are however very few resources for this client

group. This ultimately impacts on the timely delivery of intervention and potential treatment.

Question 4

ANSWER:

Is it ethical to deliver care to someone of which you have limited understanding of their culture and perspective towards mental illness, would they get the same standard of care regardless of how experienced the practitioner is?

Question 5

ANSWER:

It is difficult to keep up to date with all current projects but from my point of view stem cell therapy is one to watch for the future once legislation and government give the go ahead. The introduction of anticholinesterase has given a lot of Alzheimer's sufferers' hope but for those with other dementia's there is not the same resource. Health programmes for vascular dementia (I have recently completed a piece of research on this) are also promising but are currently only being implemented at a local level. The most significant for dementia as a whole, well nothing springs to mind.

Question 6

ANSWER:

It is time to move away from paternalism and to move towards inclusive and client centered care. If the individual has sought a diagnosis and been involved in mental health assessments then the outcome of that should be disclosed so the PWD can formulate a care plan for their future. If the individual has not sought diagnosis or been involved at a very early stage then giving a diagnosis should wait. Collusion between medical staff and relatives in withholding a diagnosis is ethically challenging. It is important to acknowledge that each individual is different but the general principle should be that on completion of the assessments the diagnosis is given (at the earliest possible time) to the individual. The medical profession does not give people diagnosed with diabetes, COPD, Cancer etc the diagnosis to the family or withhold the diagnosis (unless the information is deemed to contraindicate patient situation) so why is this acceptable in dementia care, is it because it is a mental illness and the stigma remains so high.

Question 7

ANSWER:

Society views the older person very negatively and society also portrays dementia in a very poor light, who is a positive role model for dementia that is in the papers or on the television? I can't think of any one. Society needs to change, but dementia needs to be promoted better, in GP surgeries, on

television, in schools. Funding is needed for resources to tackle these issues but lets face it the government have taken decades to even think about developing a dementia strategy so investment in dementia and the promotion of a positive understanding will continue to be done by those who champion older people and dementia care, practitioners like myself and my colleagues, the alzheimers society and carers/families and most importantly PWD.

Question 8

ANSWER:

See previous question

Question 9

ANSWER:

It should not per se be about PWD being included in the everyday life of communities but Older people should be seen as having value and knowledge. Society needs to change, what is a community any more? Traditional family units are breaking down, society as a whole places value on physical attribute and wealth and it is endemic within society that young is better. Until communities rebuild none of us have a place in it in the current climate.

Question 10

ANSWER:

Person centered care (PCC) is a term that has been banded round for years but it is not a significant feature of clinical practice. I regularly visit residential and nursing homes where everyone likes to drink tea with milk and sit in a long row watching TV. When you try to talk to staff about PCC it often falls on deaf ears or you get told they haven't got the time (what people don't realise that time is free but not exhaustive so it should be used for the maximum benefit particularly for the PWD). Person centered care should be a basic knowledge for every care provider but unfortunately 'institutionalization' has moved into community settings. PCC is helpful as it supports the person to retain their identity (and with personal identity comes levels of societal value) and also facilitates familiarity and safety. I cannot stress how highly this model needs to be taught in dementia care training, schools of nursing and medicine. It is research based and highlights that PCC can reduce so called 'challenging behaviour' and the use of a chemical cosh. If people suddenly woke me up and started taking my clothes off I would fight, does that mean i should be medicated? or should someone take a bit of time to know that my routine in the morning involves coming round a bit before having a shower? Also Lip service is paid in some environments to PCC but the reality is dementia care needs to be totally reviewed and changes made.

Question 11

ANSWER:

It is not the dementia that changes the PWD (person with dementia) identity but those around that adopt new behaviour. I've seen family members infantilizing the PWD, taking away their role, being paternalistic etc. Also care staff can talk down to the individual etc, all this contributes to the PWD loss of identity.

Question 12**ANSWER:**

If you didn't have a good relationship before the diagnosis of dementia why should a good relationship develop just because of a diagnosis? Families often disclose feelings of guilt and their behaviour can sometimes change to compensate, this can cause stress all round. Also relationships may have broken down prior to the onset of dementia and the reason for this may be due to the underlying onset of the disease. It is hard to respect values and wishes if a relative has accused you of stealing money or have been aggressive towards you. I had a relative with dementia who I loved (and I know loved me) throughout my life immeasurably, however it stays with me always that he would spit and tell me to F*** O** when he developed dementia, it's like the love is tainted however hard I try not to let it.

Question 13**ANSWER:**

The current and past views need to be examined and questions then asked such as; are there concurrent themes? Is there a solution that means the two ideologies can meet in 'middle ground'? Is there coercion or other influences that might have changed the individual's perspective? How rigorous was the belief system prior to the onset of the condition? Has there been a significant change in routine or environment that may reflect a change?

Question 14**ANSWER:**

Again it is perhaps about meeting in the middle and attempting to be cohesive with both perspectives. Consideration should always be made to the views of the PWD even if they do not have capacity and a least restrictive approach be taken.

Question 15**ANSWER:**

If there is an early diagnosis, part of this process should include the development of advanced directives or living wills. If this is not available then a decision should be made about the individuals circumstances at the time, the dementia diagnosis should not be a reason for withholding or implementing treatment. The issue should be about the least restrictive or harmful

intervention, for example if a PWD has pneumonia and clinically will improve with treatment and resume the same or similar standard of living then treatment should be considered, if the outcome is that the person would have a poor quality of life and the inevitable is only being delayed then consideration be made to making the individual comfortable and pain free. I have seen a ward putting a drip into a man who was literally in the final stages of life because he was not drinking. The man was barely conscious and all the messing about with a line and a drip was cruel. I think as a culture we are taught to fear and evade death but i think making a living will or end of life statement should be mandatory (a bit strong maybe) in the process of dementia diagnosis and post diagnostic support.

Question 16

ANSWER:

Welfare attorneys would be helpful in supporting the wishes of the PWD. However conflict is inevitable due to the medical model of doing no harm and helping the sick. we live in a litigation obsessed society and alot of the time clinicians not only have their code of practice to adhere to but a fear that if they do nothing/the wrong thing/something against the wishes of a family etc. then they will be sued and ruined. Communication is key in this area and acceptance that paternalism has no place here. Best intrests are what counts not am i going to be sued/struck off if i don't do X or Y?

Question 17

ANSWER:

This should be incorporated into post diagnostic support.

Question 18

ANSWER:

The introduction of this act is beneficial for the client and for the professional group, however as ever there is not enough training or resources to implement this right. The act is essential and will help PWD however it is yet another thing that as a practitioner I have to try and get to grips with in my own time, with limited training and with no clear practice guidelines/schematic representation of what to do. Also the act is open to interpretation (my view may differ from those from another discipline). I hope with more practice and use my skills will improve and I will be able to find it easier

Question 19

ANSWER:

Truth is important, however doing no harm is also paramount and discretion should be used (and only following multi disciplinary discussion or on consultation with family)if information potentially will cause harm. An example

would be the PWD who cannot remember her husband has died, when she is told this information she becomes very distressed and breathless. It is not appropriate to collude but other interventions should be considered e.g. distraction techniques or reminiscence.

Question 20

ANSWER:

As a practitioner I have become too worried even to positively risk manage these days, I feel I am in a blame culture and do not want all my hard work to be reduced down to a negative outcome from an opportunity to positively risk manage. Risk management is now about forms and self protection.

Question 21

ANSWER:

Define restraint, physical, emotional, social, verbal. There are so many different types each can be used depending on circumstance. I abhor restraint as a method of behaviour control either physical or pharmacological.

Question 22

ANSWER:

Yes!! again this should be a core module for anyone involved in the care spectrum.

Question 23

ANSWER:

Cost, promotion that these products exist, funding for different options not forthcoming. Ethically the issue of 'surveillance' and restriction of liberty etc comes into play but this needs to be weighted against what would happen if the PWD did not have access to the technology e.g like the man who wandered during the night and was found 3 days later frozen to death in woodland, I'm sure an ethical argument could have been made for the necessity of this technology versus loss of life.

Question 24

ANSWER:

Duty of care under the NHS and the stoppage of postcode lottery for services. The state should provide equitable care for all.

Question 29

ANSWER:

research should produce outcomes that are achievable and that are of maximum

benefit for the maximum number, additionally research funding should be disseminated to unique projects or new hypotheses and investment should be given to practitioners who are undertaking research projects as they are more likely to have a handle on the clinical pulse rather than academics who do not involve themselves in clinical care.

Question 30

ANSWER:

Too big a question to answer in the time I have left. Sorry

Question 31

ANSWER:

See previous answer.

Question 32

ANSWER:

Least qualified, least trained working with most vulnerable, e.g. the 16 year old who has just left school working in a care home or the person with no qualification or training on a minimum wage working as a home carer. Budgets determining care/ postcode lottery