

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.

European Care Group

QUESTIONS ANSWERED:

Q2

ANSWER:

a number of ethical dilemmas are confronted by families where residential type services are required. Is it ethical to hand over personal care of a parent to another - paid - individual or system? Can I really have choice as to where this care is provided? How do I know what is happening and what are my rights? when families are required to make such decisions what support and advice are they given and is it ethical that we in the profession do not provide this as well as we could and should? is it ethical that people need to leave their homes to receive care and or be charged for this and is it ethical that companies make profits from others suffering

Q1

ANSWER:

The loss of lifestyle for both the person with dementia and their immediate family is severe and of course the impacts on the person and their families social world is impacted tremendously the continuing stigma also plays a role in further diminishing the identity of the person and their larger extended family not knowing where to turn to for joined up help is a great barrier to navigating the decent into the dementia 'lifestyle' and the terrible burden placed on family carers which impacts on their financial , physical and psychological resources is great GPs can struggle both with providing diagnosis, navigating the care pathway and advising on best way forward with social and health care being split and families worrying about costs and indeed their homes many families will hold on too long before asking for help when help comes it is often disjointed and to frequently ignores the family while concentrating on the person with dementia - when it is a family centric service that is required it is therefore this realisation that dementia requires a whole family systems approach much in the way children's services are directed that would allow services to respond effectively to need and would allow families the security of knowledge that they are normal, worthwhile and valued without this understanding and funding moved towards it dementia will continue to be a very expensive but extremely poorly managed feature of mid to later life

Q4

ANSWER:

a number of ethical factors are raised by the provision of care particularly care

that is delivered in group living. immediate areas to be aware of are group norms difficult enough a subject when each group member has full mental capacity and comes from a similar ethnic and religious psycho social background when we look at adding cognitive impairment and the greater or lesser degree of respect for old age afforded by different societies congregated together we produce a social minefield. questions arise as to the appropriateness or not of faith homes or segregated living where native languages and customs are predominant? staff also find the differences between the cultural, religious and ethnic backgrounds of dispirit groups difficult in which to work and not enough training or education is provided to staff group in this respect another factor is prejudice and one feature of dementia is the roll back memory or past memory intrusions which can take a person thinking to a time when cultural prejudices were stronger than today and it was more socially acceptable to make prejudices known and to openly use racist and prejudicial language - this can cause difficulties, resentments and tensions among those using the service, residing in the care arena, those needing to provide care and to families overhearing such interactions the emphasis should fall to the providers and purchasers of care to fund training and education for all where care is delivered in multi racial, multi faith units

Q3

ANSWER:

I do not think that the ethnic differences between understanding dementia as such really make much difference to the response to need however cultural differences to the caring process do make considerable differences many cultures even in the 21st Century find it difficult to accept that older persons in need are taken away from families and cared for by paid carers many more find the culture displayed in these safe environments harder to accept. it is my finding that although social groupings can make considerable demands on people to confirm that most people try to reset the negative aspects and try to forge caring relationships even in the midst of social degeneration supporting minorities is however a hard task and we need to support the three way construct of partnership once someone has entered the care environment - Family - person with dementia - staff member - this way environmental pressures would be resisted by a reliance on previous social norms

Q5

ANSWER:

Neuroscience probably holds more keys to understanding the behaviour and responses of those suffering dementia than any other field but these sciences are either not introduced or ignored where dementia care is taking place whilst the development of cures and treatments of a pharmacology or neuro procedural means are being explored the millions of persons suffering currently are often subjected to care that is at best well meaning and at worst abusive this is more often than not completely unintentional but comes from simplistic or no training

understand how brains work in their normal state and how these may operate differently under trauma conditions is the missing link in modern care it is a difficult and often intimidating field but with effort methods can be found to translate the astounding current knowledge base into methods or training, designing buildings and delivering care that would far outstrip current practice this needs to be a serious area for future investigation and funding

Q6

ANSWER:

This is an individual choice as they are individual members of society with dementia a sound understanding of the patient's life history, support network and previous coping abilities all need to lead to the decision to discuss diagnosis however with the legal system now gearing up to allow living will - advance directives and such an early discussion as to the implications of diagnosis should be on offer to everyone - it remains however an individual choice as to use this information or remain without it

Q9

ANSWER:

communities experience dementia and people with dementia experience communities they are one and the same why do we discuss them in different contexts? if dementia was promoted as an everyday experience of many families and communities barriers would fall but as long as we continue to segregate and use the language of segregation and labels we assist in the stigmatisation of those around and within who experience cognitive decline through degenerative process

Q7

ANSWER:

dementia is seen as a disease of old age and as such affects them and not us - society shuns this kind of engagement however much more needs to be done to allow the everyday man and woman to understand the effects of dementia - the positive approaches that are available and we need to be able to promote the idea of dementia as a family centric process dementia does not arise in isolation its effects carry across families, generations and communities - the more this is discussed and understood the more accepting the public will become we professionals also have a role to lead this refocusing as to often in our attempts not to be alarmist we ourselves describe dementia as 'not the norm' when in fact it is a normal part of our society that is not an inevitability for each individual but is an inevitability for society

Q8

ANSWER:

stigma remains a strong deterrent in the provision of highly visible transparent care and care systems most persons believe dementia is a mental illness in the same sense as the group that includes psychosis and that those with dementia are dangerous and violent when discussing dementia with the lay person they will reveal that the demented are aggressive, wandering, incontinent, pitiful souls that need to be locked away for their own good in the 21st century we should with the media available to us have redirected public thinking on this issue by now however we remain in the dark as the subject remains a strong taboo perhaps it is the terminology we persist in using and the fact that all dementias are seen as one disease process and care generally lumps all persons with dementia irrespective of differing ages, culture, religion and diagnosis in one large locked building when they are assigned to care society creates stigma and maintains it - education, exposure and money are required

Q10

ANSWER:

The idea of having a person centred approach has revolutionized the language if not always the practice of dementia caring. it is a vague concept and has proven difficult to grasp at shop floor level and this is mainly that the idea of person centre care involves a relationship approach which is difficult in situations where care is provided by one person to many as in care homes, hospitals, day care etc a model which promotes the person as part of a system is further needed to be strengthened but the use of complex theories when tackling this issue like the social constructivist only further complicates the issue

Q11

ANSWER:

as with all processes that cause disability form the norm this is life changing the issue with change of personality in persons with dementia is complex and does of course involve the changes in brain structure and chemistry however it also involves the change in how a person views themselves as they begin to lose the ability to cope with the world around them and also how the persons view of themselves as a part of society changes as society begin to view them as 'different' of course as dementia also carries a stigma even inter family relationships alter and the person begin to see themselves as less than they were

Q12

ANSWER:

The unfortunate occurrence of mood changes and lack of social inhibition is that it reinforces the stereotypical stigmatic view of dementia as changing someone's personality and that they become 'no longer the same person' this schism in thinking could be changed by education and more publicity but as long as soaps and other cultural touch points paint the picture of dementia as being

rapid and involving completely character change we will need to work very hard on public knowledge and opinion

Q14

ANSWER:

Multi disciplinary and family centric approaches must be considered best interest here - where by the opinions of all including the person with dementia must be honestly appraised - medics should not receive a priority or majority vote when capacity is only just beginning to loosen

Q13

ANSWER:

the tricky question of living wills etc are encompassed here and we move into the arena of does altered brain structure and function constitute the person as they are now or the person they once were as being the relevant touchstone clearly someone adversely affected by changes in function who now have no understanding or regard for their own or other safety can not be deemed as legally responsible as some one with fully functioning capacity but preventing someone from taking actions that make them happy now because it may not have made their old selves happy is difficult clearly capacity needs to be assessed and then a view taken as to the appropriateness of decisions taken with the degree of dementia and the past life and history of the person being considered now effecting current decisions the decision to stop someone from doing should only be taken in the best interest as defined by the capacity act and should not infringe basic rights except where life becomes threatened

Q15

ANSWER:

at the heart of this must be the family and decisions can only be made individually expressing all the past beliefs of the person and encompassing current quality of life a strong religious element will play an important role here where some kinds of passive death are seen as assisted suicide the decision currently would fall to the attending professional and as it stands this is probably correct - using all the mechanisms of informed debate as if life is purely sustained and unpleasant a decision that lacks the passionate content of grieving families may best provide a solution

Q16

ANSWER:

the history of social vs medical input is great with each one believing the other to either be too passionate or lacking involvement emotionally the legal framework of the UK allows for disputes to be settled under law and in extreme cases this should be seen as the ultimate resolution however for minor disputes

previous wishes and needs of the person themselves and their family should be the factor that adds weight to either argument

Q17

ANSWER:

as previously mentioned as brain structure and chemistry changes and as the person evolves through their position now in society new people emerge - past wishes can only remain relevant where life or death is concerned as the new person can not themselves be held prisoner by past beliefs people with dementia are no different to you or i in developing their roles and personality in response to our wants, needs wishes and those of society - if i had made some advanced directive at 20 it would certainly become an embarrassment and hindrance to me today

Q18

ANSWER:

on the ground evidence seems to show across my organization that this new element of provability has caused professionals to doubt their instincts and has added to the workload however conversely the depth of knowledge required to understand and make judgements about the persons ability, capacity and best interests has developed a more person centred approach the issues will become more difficult when third parties now act in ways that may not in anyone's understanding appear to be in the best interests of those they represent by using advanced directives etc and this is a grey area that only time will clarify

Q19

ANSWER:

the concept of validation therapy clearly indicates that we need to view the world from the perspective of the person with dementia and therefore imposing our world or our moral standpoints upon them is unethical and can be cruel for instance a lady asks everyday if her 'mother; will pick her up from school' the reality is that she is an old lady with a degenerative process and that her Mother died 36 years ago - she is provided with this truth and becomes distressed and inconsolable each time she asks - is that what our truth requires of this lady? In validation the current truth is observed and the conversation revolves around acknowledging this needs of the lady and although the first works may be about the 'assurances Mother will protect and collect her the rest of the conversation uses reality to assess how the 'needs' expressed through the language of 'mother figure' can now be met lying non therapeutically however can never be accepted and it within the intention of the intervention that the facts must be examined

Q20

ANSWER:

Yes - it is an unfortunate reality that under current guidelines and fear of prosecution that much liberty and freedom that could be assigned to the person is restricted a degree of risk is acceptable to you and me as we live our lives but not to those we deem less than ourselves - the question is in what way can someone be assisted to express freedom and risk and how can the level of risk be assessed and then provided safely for at all times anything but risk of physical or psychological harm should be encouraged as normal and preferred

Q21**ANSWER:**

Restraint under certain circumstances allowed and controlled by law and best practice but the issues comes down to interpretation and intent restraint in the form of locked doors telecare devices, tracking and tagging, chemical and other should be regulated, recorded and assessed by a multi professional contingent - where the risk of abuse occurs is in the amount of people consulted into the use or not of restraint - the less debate and option the more chances that individual abuse or curtailment of rights become possible

Q22**ANSWER:**

it is an essential element of all caring practices but is too often assigned to a footnote or not at all the ethical use of power and the realisation of moral aspects of the care process should form the lynch pin of all training programs and be as high up the curriculum as possible - this then would have a trickle down cascade effect into all other areas taught informing and shaping individual interpretation and opinion

Q23**ANSWER:**

it is a part of the human condition to expect freedom - in certain societies where freedoms are restricted telecare and tracking would not be seen as evasive or destructive to liberty - in the west they are the first thing is that these technologies and their purposes are not fully understood and the fear of the person behind the technology looms large making lawful and legal uses of these technologies would help to quell the fear of the big brother approach if being electronically monitored allows the individual to roam at will then this is a good thing but convincing a sceptical public of the ethical and morale astuteness of the person who installs or monitors the tag is a more relevant issue

Q24**ANSWER:**

the NHS has forfeited in many senses the morale upper hand in the treatment

and care of people with dementia by its adherence to NICE guidelines and cost cutting initiatives across older persons services but again paradoxically provides memory clinics etc that are not profit making and are therefore generally not available in the for profit sector does the state owe its citizens a service - he way our constitution is designed yes it does and under these acts people who lose capacity or become unwell are entitled to care free at the point of delivery where we believe that the strong should protect the weak and that the constitution of the land is democracy we continue to care for those who are reliant upon us financially also through the income tax and national insurance contribution people pay into the upkeep of the state and the state accepts certain obligations in return

Q25

ANSWER:

the basic needs of the family do not change even as dementia progresses to think that their in some way becomes a cut off point is to miss completely the family dynamic - relationships continue even as they reshape and blur what is best for the person with dementia is what is best for the family as a unit - one can not assume priority over the other in care we have divorced this understanding it may be in the families best interest where abuse or neglect is occurring that one of their members be cared for away from physical contact that does mean the unit ceases and all efforts should be made therapeutically to work with the whole family irrespective of if they ever are in the same room again

Q26

ANSWER:

this is a very well worded question as it recognizes the power of the family and that professionals are outsiders looking in - the dilemmas of working with families are many and this always arises when dynamic interactions are distorted through illness of adverse social standing or poverty or financial hardship as is often the case for families trying to cope with the effects of dementia the problematic issues for support staff are that we tend to assign worthiness based upon our own preconceived ideas of what types of behaviours or responses would be 'approved' by us multi agency approaches where the family remains the centre of all activity are the only real methods of 'removing' these understandable intentions

Q27

ANSWER:

In all circumstances - in systems thinking one does not remove an object or we have two separate systems - families are dynamic systems that we do have the right to dissolve - some primary individual needs may emerge but these should be seen in context of the larger intertwined relationships and dealt with

accordingly

Q28

ANSWER:

individual confidentiality is different from family unity and as professional their needs to be the understanding that this is a right. also in law some forms of information are held as confidential to the professional - the right to withhold information should always and only be based on best interests and not for the sake of the organization where best interests are considered then it seems ethical that information which would have destructive or terminal effects be debated among professional and a measured judgement applied as to what is to be divulged and at what time the lack of clear guidance creates professional and family schisms however this lack of a definitive can or can not is correct in that every case needs unique understanding once a situation is clearly understood the person responsible has made a morale decision based on their beliefs as to right or wrong this should be no less respected as the individuals right to know

Q29

ANSWER:

better understanding, better education and acceptance, better care and prevention and cure funding should be allocated on the immediate good that research will have on the welfare of those living with dementia, those at risk of developing and of supporting society as a whole to understand and accept those effected or on the basis that the research will influence these factors in the future

Q30

ANSWER:

this again comes back to the greater good of the family or the community - once capacity has been individually lost the collective involvement in the family and society does not recede where research may effect the better good of society in the future and the family as a whole have deemed the research acceptable to them then professional should not stand in the way however even when professional know that a greater good could be achieved with out the immediate consent of the family research should not be permitted

Q31

ANSWER:

No - an ethical framework - not so much a morale framework - should be applied to all research

Q32

ANSWER:

government financial allocation has a severe impact upon the lives of those with dementia and their families and this should be considered and debated at some point as government prioritise the morale and ethical needs for them to understand deeply the effect of a population projected to grow by almost 1 million people in the next 20 years this is now more pertinent than ever