

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.

Age Concern Camden

QUESTIONS ANSWERED:

Q1

ANSWER:

For individuals with dementia the memory loss, cognitive impairment and confusion coupled with the frustration and sense of disempowerment that can accompany these aspects are the most distressing. Also being labelled by their symptoms and diagnosis adds to their disempowerment and can contribute to becoming isolated and socially excluded. For carers, isolation, role reversal, the stress of caring for someone who may display unpredictable behaviour and who becomes increasingly dependent are what I have witnessed to have the greatest impact. Both carers and people with dementia need support and information that is easy to access and support and services which can be individualised and accommodate their unique needs. Support should focus on providing interventions which will increase a sense of wellbeing and self worth. Advice and information should be more easily available and accessible to people with dementia and their carers. Support should not just focus on medical models but should also promote choice and independence.

Q2

ANSWER:

The issue of restraint; in my career I have frequently dealt with both formal and informal carers whom in their desire to 'protect' individuals with dementia, attempt to undertake actions which will restrict freedom and not allow for any risk, even when these actions will result in distress for the person with dementia.

Q3

ANSWER:

from my work with BME communities, many have a poor understanding of dementia, I have also encountered misconceptions about dementia and it's causes. This also results in these communities having a poor uptake of services for people with dementia. Some communities older population also have expectations based on their cultural expectations that their families will take on all their care needs, in this current age this is not always practical or possible.

Q4

ANSWER:

To truly meet the needs of individuals with dementia, then service need to be available which can respect cultural differences. This is not always the case and I have witnessed individuals referred to services where the environment is alien and workers are ill equipped to understand or meet their needs, this results sometimes in support which actually distresses and can be of no benefit.

Q5

ANSWER:

stem cell research which may result in advances in brain cell growth or repair.

Q6

ANSWER:

Early diagnosis can ensure that individuals receive appropriate medical interventions and support. However some individuals may not require any interventions in the period after diagnosis and there is a danger that these individuals may 'disappear' until crisis intervention is required. When people are diagnosed there should be a support pathway in place for their journey rather than for just when they have pressing need. I believe that diagnosis should be offered having taken into consideration the individuals wishes and circumstances. Some relatives may wish to protect their relative from the diagnosis and this may result in an individual being disempowered and denied the opportunity to plan for their future. Medical professionals should consider the needs of the individual with dementia firstly as they are the patient.

Q7

ANSWER:

Public awareness should be increased and education about dementia may help to increase understanding and recognition of dementia. I believe society in general has a poor understanding and this can result in people with dementia being stigmatised and socially excluded through fear and, ignorance. This could be achieved through health promotion and education; better access to memory clinics; improved primary care and GP support and the media giving accurate information that does not just portray negative experiences and outcomes. I would also like to see education of children and younger people and inter generational activities undertaken.

Q8

ANSWER:

From my work I have witnessed first hand attitudes and behaviours from professionals that result in stigmatisation. For example, care home staff insisting on using separate crockery and toilet facilities, Health and Social care workers ignoring the person with dementia and talking over them and behaviour being

attributed to the person having dementia rather than trying to understand it.

Q9

ANSWER:

As we are an aging population and more people develop dementia then society should be seeking to ensure these people are supported within their own communities and remain a part of the community. I have witnessed this working where there are mainstream services that can also seek to meet the needs of people with dementia and also through initiatives such as Good Neighbour schemes and befriending services which are community based. Also care homes should seek to engage residents in activities which enable them to continue community based activities and interests and that involve members of the community also coming into care homes.

Q10

ANSWER:

To truly see a person with dementia as unique and to recognise them as the individual they are then person centred care is crucial. As their condition progresses person centred care enables professionals to understand and empathize with a persons reality and feelings. by appreciating a persons past and life history we can then attempt to understand their reality better.

Q12

ANSWER:

often I have witnessed those close to people with dementia struggling to come to terms with changes in mood and personality.

Q11

ANSWER:

Some characteristics may change but they are still the same individual and their personality and biography will contribute largely to their experience of dementia. A persons values and what was dear to them should not be ignored because of their diagnosis.

Q13

ANSWER:

By taking a person centred approach which does consider their values and wishes before diagnosis but that also considers the impact of any decision made on their life as it is now and how their well being may be affected.

Q14

ANSWER:

it is important to not write off that person as unable to give an opinion. They may still be able to indicate or communicate satisfaction or dissatisfaction which would help in making decisions. They may be able to make a decision based on less information or about a related matter. It is important that the mental capacity act is followed and that individuals are given the opportunity for each decision that needs to be made.

Q16**ANSWER:**

independent advocates should be used when there is disagreement.

Q17**ANSWER:**

when individuals are in the earlier stages of dementia when they may still have capacity and can express wishes regarding this issue then it should be discussed with them so they can choose to make an advance directive should they wish to at that time.

Q18**ANSWER:**

as an advocate I have witnessed statutory services take more responsibility for ensuring a person is consulted with or their opinion sought. However I still encounter an attitude of 'they haven't capacity' without exploring each decision with the person.

Q19**ANSWER:**

if the truth will cause distress, for example if a person is asking where their mother is, I do not advocate lying to that person but exploring why they are seeking their mother and what other emotions they may be experiencing will be of more benefit than telling them that their mother is deceased, and trying to return them to our reality rather than validate what theirs is.

Q20**ANSWER:**

Risk should be managed to minimise risk and negative outcomes but in balance with ensuring that an individual's liberty and rights are not restricted. We all have the right to make unwise decisions and show poor judgement and people with dementia should not be over-protected when it results in a loss of independence or choice. Carers should also avoid passing judgement on behaviour and

attributing all actions to the individual having dementia.

Q21

ANSWER:

in professional settings such as care homes risk assessments should involve the person with dementia or their advocate, and any restraint should involve the minimum appropriate restrictions. However a duty of care can cause conflict when making these decisions, the dilemma being how do you protect someone without using unnecessary restraint whilst not restricting their freedom and right to choose, even if their actions may result in injury to themselves. In an informal setting carers may often use restraint methods which in a professional setting would be deemed unacceptable, for example locking a person in, tying someone to a chair, and these actions are usually taken through a desire to protect their loved one.

Q22

ANSWER:

Training is crucial in order for workers and carers to understand the implications of their actions and also in order for them to explore and understand behaviour which is often wrongly labelled as challenging. However within professional settings attitudes and culture are paramount in order to ensure support and decisions are appropriate, there should be clear guidelines and also leadership which cascades from organizations and management.

Q24

ANSWER:

no individual asks to be diagnosed with a progressive conditions such as dementia and as such they should be given support.

Q25

ANSWER:

The use of specialist advocacy services which will represent the wishes of an individual with dementia. Also through better education and information for carers

Q27

ANSWER:

if it is in the best interests of a person with dementia to remain with their partner or family, judgments may be needed that allow for this. for example if a couple need to separate in order for appropriate care to be given rather than considering a more costly package that would enable them to remain together,

Q26

ANSWER:

it can be difficult as both parties may have differing individual needs, their client may be the person with dementia but that individuals diagnosis may be causing ill being or issues for the carer or family member who is not their client.

Q28

ANSWER:

it may be that a relative may have crucial information that would enable the person with dementia to receive better care or treatment. also a family member may have information that will help professionals understand an individuals behaviour or actions

Q29

ANSWER:

a greater understanding of the condition, prevention and treatments that will delay or improve symptoms

Q30

ANSWER:

again it would depend on the individual and their previous wishes and beliefs would need to be considered. An independent body should decide if research should be permitted.