

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.

Canon Professor Robin Gill

Q1 In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most by people with dementia and those caring for them?

From a subjective perspective, being helpless and in need of care because of dementia might well seem like a great indignity, especially in a society such as ours which puts a premium on autonomy and independence. But this does not mean that persons with dementia have lost their intrinsic human dignity. Philosophers have argued that people with dementia:

"...should be retained within a circle of protection, because we remember what they have achieved and we honour their biographical past." Sutton comments: "Rightly so, for surely (all) those who are ill, dependent and dying remain our fellow humans. As such they never lose their dignity." (our emphasis) ¹

To be cared for by others requires trust in the carer. It requires recognition of the carer as caring and of the importance of human community.

Clearly the direct, day to day impact on the lives of those suffering from, or caring for those with, dementia will vary from case to case and community to community. Dementia is a major illness and it can be a real shock for people to discover they or their loved ones have it. It is frightening for patients because they no longer have the same control over their lives and actions, and they know that this will worsen over time. Moreover, there is less moral support for them than sufferers of other conditions like cancer because of the stigma associated with dementia. The impact on carers is manifold. Many primary carers will be elderly and have a fear of aging, a fear of not coping and a fear for their own health. They will tend to worry about all the decisions and experience problems with handling personality changes in the patient.

The need for support is universal. Whilst families may be expected to take the bulk of care and decision making, it may be that neighbours actually provide frequent day to day practical care and help, being the nearest on the ground. Both frequently fail to have sufficient practical and financial support to fulfill these roles.

In our view, there is insufficient statutory support for the increasing demands being made on carers and resources, so that difficult decisions are being made about priorities, with the inevitable result that some sufferers fall through the

¹ Sutton, A., *Christian Bioethics: A Guide for the Perplexed*, T&T Clark, 2008, p54.

gaps. Furthermore, lack of sufficient statutory funding leaves no room for real preventative care and action so that, in many situations, mild cases of dementia can be exacerbated, worsen and ultimately more resources are required to deal with them. Preventative care not only helps the individual and their families but is more cost effective and less wasteful of limited resources.

As well as general concerns about statutory funding and support, we believe there is a need for more trained volunteers to provide care in the community and more home support. At the moment much of the statutory home support is limited to certain times of the day (for example after 9am) and to specific duties, which may fail to provide holistic care that would best benefit the patient. In Q32 we highlight and commend a working model of community care that provides the kind of support needed by patients and their carers.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

Many ethical dilemmas ultimately centre on the decision-making capacity of the dementia sufferer. For example, who decides about care plans? Social services or those on the ground? Who is best placed to know about, and decide on, best interests and will this be to section the patient or leave them in their home? How should a patient be managed if they disagree with a plan? (but perhaps live in a different era in their minds?) And what involvement should the family have?

Q3 From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

The care of those with dementia can strongly depend upon the sufferers' resources and support network, particularly if they know and understand the illness, how to draw upon services and can help and speak on behalf of the patient. Clearly therefore a lack of financial resources and/or a network of able supporters can hinder access to care. This may vary according to social groups and is likely to particularly impact any marginalised individuals or groups.

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Sufferers of dementia will often revert to their original birth language, which can cause problems if they are being cared for in a place where no-one understands their language or culture. Clearly it is preferable to ensure that patients are matched with care homes that are able to provide staff who can understand their food preferences, language, religion and familiar traditions.

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

An issue such as this can really only be dealt with on a case by case basis, depending upon the support required and available for the individual from within the community and from those close to the individual.

It is important to note however that with any early diagnosis, emphasis must be on providing preventative care and action where possible.

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

In our observation, society generally considers that dementia (and indeed growing old) is to be feared. As we state in Q1 and Q8, there is also stigma attached to it. Most people are distanced from dementia and have little real understanding of it, unless confronted directly. This can impact the number of volunteers who are willing and able to work with patients. Therefore public education and understanding about dementia is essential.

Awareness weeks organised by the Alzheimer's Society can be effective at awareness raising, as can collections in supermarkets. GP surgeries are variable in their understanding so more effort in improving their awareness would be particularly useful. See also Q9.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

Stigma is a symptom of a lack of understanding and fear of dementia. We would recommend that more be done to include people with dementia in community life. This is both beneficial for those with dementia, as part of their holistic care, as well as for improving awareness and understanding of it more generally (see Q9).

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

People predominantly thrive best within community, not isolation. Those that live on their own, or in isolation, can tend to become self absorbed and deteriorate more rapidly than those involved in community life.

We should be aspiring to involve patients in community life as much as possible, for example, using sudoku matches, quizzes, pub lunches, bowling, swimming, golf, computer sessions and other conversational and social engagement opportunities. Drop in centres, sports and other clubs are all valuable sources of

contact, and can provide dementia sufferers with valuable and beneficial opportunities to mix, share and talk with others on 'the journey'. Similarly, carers also need support and involvement within the community.

It is also important to have volunteers who can help sufferers get out and about, to act as befrienders, to talk and walk with them.

This is part of all round holistic care for patients and will rely on seamless services between agencies (see also Q10). The cooperation of involved agencies is essential in caring for those with dementia. Each community should aspire to provide seamless services and support for each other if they are to really address person-centred care, and not allow individuals to slip through gaps (see Q32).

Person-centred care and personal identity

Q10 Is the idea of person-centred care helpful, and if so, in what way?

The concept of person centred care is helpful, although the reality of patient centred care on the ground is not always evident.

CARE strongly believes that a person is not just a physical being but is holistic - a psychological, social and spiritual being – and thus should have holistic care. Holistic care would be evident in provision of intervention measures that specifically aim to prevent further mental deterioration for those with dementia (such as those described at Q9 above) as well as low level support measures. This would include, for example, shopping help, cleaning services, constancy with home support workers, opportunities for social engagement, spiritual care, peer connection, etc.

The relationship between patient and home support workers is vital, and is most effective when there is a good relationship between the two, so that there is constancy and understanding of the person, their needs and routines.

Given the importance of a spiritual framework for some people, it is vital to ensure that the mix of service providers includes those operating in a faith ethos. The concept of person-centred care is one that has been foundational for many providers and carers operating within the distinctive Christian Voluntary Sector, who are concerned to provide holistic care within local communities for those with a faith and as well as those without (see Q32).

Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?

Frequently a dementia patient loses their identity and cannot remember who they once were. They can also experience personality changes. However family and carers who do know the individual have an important role to play in

ensuring that the individual's specific needs, likes and dislikes are catered for in order to ensure appropriate care (e.g. a clean house, clothes, hairstyles, hobbies etc).

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

Whilst it is important to respect the values and wishes of patients, the reality is that the family may not be able to cope with care. This will usually be a difficult decision for a family that has hitherto provided the bulk of caring particularly if it means that a patient's preferences will have to be over-ridden. Decisions about care should be made in conjunction with other agencies (social services, GP's etc), partly to take some pressure off the family but also with the aim of looking to keep a patient in their own home for as long as realistically and practically possible for all those involved. Financial considerations should not influence decision-making.

Making decisions

Q13 When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

At the heart of the Mental Capacity Act (MCA) lies the fundamental tenet that all decisions taken on behalf of someone who lacks capacity must be taken in his/her best interests. This is a statutory codification of the existing common law position.

The legislation does not define 'best interests' but gives a statutory check list of factors that must be considered when making a determination of what is in a person's best interests.

A 'best interests' judgement is NOT an attempt to determine what the person would have wanted, although this must be taken into account.

Rather, it is an objective test of what would be in the person's actual best interests now, taking into consideration all of the relevant factors, including the person's past and present wishes and feelings and the change in circumstances.

Q14 What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

Under common law it has been clear that where an adult lacks capacity to make decisions on his or her behalf, health interventions will be lawful where there is a necessity to act and the action is in the best interests of the incompetent adult. The MCA clarifies this aspect of common law by giving legal protection to

decision-makers in these circumstances. Capacity to make decisions is set out in the MCA.

A person is regarded as being unable to make a decision if, at the time the decision needs to be made, he or she is unable:

To understand the information relevant to the decision;
To retain the information relevant to the decision;
To use or weigh the information; or
To communicate the decision (by any means).

Where it is determined that an individual lacks capacity, whether only 'just' or not, any decision or action taken on his/her behalf must be in his/her objective best interests. What constitutes an individual's best interests will depend upon the circumstances of each individual case (see also Q13 above).

Q15 How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

The case HE v A Hospital NHS Trust makes clear that a patient's anticipatory refusal of treatment will NOT survive a material change in circumstance. This is also clear in the MCA. In the absence of any valid advance directive, doctors must treat a patient in his/her current actual best interest, namely holistic care and the preservation of life.

Decisions should not be influenced by perceived quality of life criteria because every patient, with or without dementia, should be equally valued and provided with the love and support of others.

Q16 What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

Under the MCA the lasting power of attorney is constrained by the basic principles of the MCA and must make decisions in the best interests of the incapacitated person. The transfer of health decision-making authority must be indicated in the Lasting Powers of Attorney (LPA) and does not extend to life-sustaining treatment unless this is explicitly stated.

Clearly the more powers that are given to welfare attorney's the more potential for abuse, especially for treatment refusals. It is not always guaranteed that an attorney will make wise decisions, even if made in good faith. Nevertheless, it will often be the case that someone does need to be appointed for decision-making and in such cases it is important that all those involved - the attorney

and health care professionals - work in full cooperation in order to reach joint agreement on the patient's best interests.

Where a doctor has significant concern relating to decisions made under an LPA about serious medical treatment, or if there is doubt or dispute about whether a particular treatment will be in a person's best interests, the first step will be to ensure that there is proper discussion about it. Although in cases of continued disagreement the MCA does provide for referral for adjudication to the Court of Protection, it will inevitably be the case that many health professionals take the path of least resistance and will prefer to avoid legal challenges to the attorney. Indeed, there is a concern that the role of the Court of Protection and Proxy Decision Makers could effectively take the role of professionals out of the picture, with the result that Best Clinical Practice could be over-ridden. So whilst the law is generally protective of patients, ultimately good or bad practice will depend on what happens on the ground.

Over time it is hoped that the Court will build up specialist expertise in matters involving incapacitated adults and that this will lead to the more straightforward resolution of disputes. There are also certain controversial treatment decisions (stipulated in the MCA) that should be referred automatically to the Court but generally it should be a last resort for solving disagreements.

Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

The legality of valid and applicable advance refusals of treatment has been established at common law (Re AK, HE v NHS Trust). The MCA codifies and clarifies the current common law rules but is restricted explicitly to advance decisions to refuse treatment. Treatment preferences may be relevant to a broader 'best interests' assessment but are *not legally binding*. It may be that more clarification is required so that those involved in decision making on behalf of patients are more aware of the limitations and restrictions within the law.

The first test must always be, is the advance directive valid and applicable? The longer ago that it was made, the less weight it will have. If it is over-ridden verbally or withdrawn, it is not binding. Nor if the patient was or is unaware of new treatments or has significantly changed circumstances. Nor if the person making the directive has appointed, after the directive was made, an attorney to make the specified decision. In other words if there are reasonable grounds to doubt its validity, it is not binding. In which case, treatment decisions must be made in the patient's best interests. If of course the AD is valid and applicable but is perceived as being a 'bad decision' then there is little that can be done.

It is already the case that AD's will only apply to life sustaining treatment where it is in writing, signed and witnessed and contains a statement that it is to apply

even where life is at risk. [AD's cannot be used to refuse warmth, shelter and hygiene but they can be used to refuse artificial nutrition and hydration.]

We do not encourage the completion of advance directives. Much of the motivation for setting out preferences in such a form relates to fears and anxieties over the mode of dying. It is clearly useful to the doctor and, indeed to other carers as well, to have the priorities, desires and attitudes of the patient made plain. Such a document, however, cannot cover all possible future events since these cannot be accurately foreseen. Changing circumstances may render it irrelevant, inappropriate or even obstructive to the best care indicated for new circumstances. Where mental capacity has been lost, if such a directive were to be binding, the best management may be precluded.

Like legalised euthanasia, advance directives, if held to be binding when applied by others could be open to abuse and extremely difficult to make safe. As stated in Q16 above, the empowerment of third party proxies to refuse treatment carries risks, especially if the person given such responsibility is not made accountable for the decisions made. In any system of binding advance directives or refusals, there is little room for change of mind in changing circumstances.

While we do not take the position that "Doctor always knows best", nevertheless we do believe that a trained and experienced professional person is more likely to make a sound clinical judgment than someone without such knowledge. There is much also to be said for the "second opinion", or even for the third, fourth or fifth, but these should be informed opinions. A good relationship in which clear communication takes place between doctor and patient is consistently better than any piece of paper, no matter how well drafted it may be.

Q18 What are your views about the effect of the Adults with Incapacity (Scotland) Act 2000 or the Mental Capacity Act 2005, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

We believe that it is always preferable and more respectful to tell the truth. Of course there are circumstances in which it may appear to be preferable not to do so, but there are usually other ways to achieve an objective. For example, it is often possible to persuade and convince a patient to do something, or to take them back to reality, or to divert a patient, or give them some space etc.

The solution here is to ensure volunteers and staff are properly trained. It requires skill, practice and sometime pre-planned strategies to find the right way to tell the truth or to persuade an unwilling patient. Trained staff should be able to orientate a patient back to reality, to cajole a patient respectfully, to not make a patient anxious and indeed to not aggravate the dementia further.

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

The answer to this will depend on the individual situation, the patient and the carer's attitude and skill, and we do not feel it is appropriate to give a blanket response.

Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

Common law and the MCA do legitimise the use of force or restraint but limit the extent to which the freedom of movement of an incapacitated person can be restricted:

An incapacitated person can only be restrained where there is a reasonable belief that it is necessary to prevent harm to the incapacitated person;
Any restraint must be proportionate to the risk, and of the minimal level necessary to protect the incapacitated person;
The onus is on the person wishing to act to objectively justify his/her belief that the person being cared for is likely to be harmed unless some sort of physical intervention or other restraining action is taken.

Generally, we would not advocate the use of restraint, physically or pharmacologically. Dementia requires staff and volunteers that are patient and compassionate, and often specialist. Using restraint can frequently lead to distress and exacerbate a situation when the reality is that most patients need space and freedom.

There are other concerns with restraint, such as a risk of abuse and over-use. When some pharmacological intervention is deemed to be required this must always be monitored carefully and only once alternatives have been explored.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

It is essential that thorough training is provided for anyone working with dementia patients. Guidance is also needed because this is a specialised area, requiring compassionate and skilled staff who are frequently having to make

difficult decisions. Guidance will also help all agencies who are working together to achieve the same objectives.

Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

These new technologies generally recognise the importance of freedom for patients and should be considered in terms of a patient's need to walk or be outside. The need for regular fresh air and exercise would require either a companion, a safe courtyard, a safe garden or would require a tagging system. Clearly the former are preferable (indeed, every Care Home should have a safe courtyard or garden) but in their absence tagging could be considered. However there are issues that may limit its widespread acceptance. For example, the cost, the reliability and the practicalities (such as whether to put a band on a wrist or around a neck to prevent its inadvertent removal). tracking devices also raise issues of privacy and restraint and potential abuse. These are complex issues that will often depend on an individual's circumstances and surroundings.

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

The duty of the state and community, is to value those with dementia. As we stated in Q1 those with dementia should be retained *'within a circle of protection, because we remember what they have achieved and we honour their biographical past.'* To be cared for by others requires trust in the carer. It requires recognition of the carer as caring and of the importance of human community.

This is likely to not just require better training and guidance but increased statutory funding of services and care.

Furthermore, as already stated, we would like to see improved understanding and education of dementia, on what it is and the implications for carers. We would like to see the removal of society's fear of dementia, which fundamentally derives from a lack of understanding of it.

The needs of carers.

Q25 How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

In many cases there will be enormous pressure on the family caring for the patient. There is always a danger that the carers will burn out and need support

as much as the patient. Clearly this is best prevented through provision of a caring ministry for carers themselves (see Q27 and Q32).

Practically, we would want to see statutory services providing more support, such as more respite care, which is a source of real help and relief for carers. It can take two weeks for a carer to feel relieved of the pressures, but if there is only two weeks respite care provided for, this will be insufficient time for recovery and restoration.

Q27 In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a couple (or of a household), instead of concentrating solely on the interests and needs of the individual?

It is essential that the provision of holistic care for the patient takes into account the practical needs of their carers at the same time. As a general rule, the separation of couples should be avoided as much as possible – a spouse/partner can be a familiar voice and presence for a patient and can provide advice as to appropriate care (including medication, drugs etc), likes, dislikes and familiarity. This will be beneficial to the patient as well as their spouse/partner.

In situations where just one spouse/partner is in a Care Home, the other partner must be easily able to access the home for visiting. Therefore the location of the Care Home must be taken into consideration - either the home must not be too far away or there should be reliable public transport to it.

Q28 From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

There should be a balance in funding research that looks at both cures as well as the causes of dementia.

Q31 Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research which you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

Other issues

Q32 Are there any other ethical issues relating to dementia that we should consider?

We would like to take the opportunity to commend a working example of community care that provides an excellent model of best practice in caring for the vulnerable, including those with dementia.

The *Evergreen Trust*² based in Stamford, Lincolnshire, aims to promote holistic health in individuals and healthy attitudes towards ageing, challenging age discrimination and negative social expectations.

The *Evergreen Trust* has grown to 26 paid staff, and 110 registered volunteers in just over 3 years. The Trust is supported by churches and agencies (including charities, police, businesses, social services and medical services) all working together in the community.

The mission statement is:

"The promotion of healthy ageing involves working to build self-esteem and to restore social status, improving the circumstances of ageing and vulnerable people within the church and wider community. The Trust will seek relevant ways of supporting people, and dedicates itself to providing practical assistance for those living in the community. Where there is singleness of purpose, the Trust will work with Health and social Services in achieving holistic care in the community."

It achieves this through:

1. Home support services – helping with domestic, shopping and laundry needs
2. Volunteer services – including a popular befriending scheme, meal provision, a clean team and a hospital to home support team.

This model template can be picked up by any community prepared to work together to support and provide for some of the most vulnerable in our communities.

Philippa Taylor, CARE's Senior Family and Bioethics Consultant

Dr Dan Boucher

² The Evergreen Care Trust, Ryhall Road, Stamford, Lincs PE9 1YA. Tel 01780 765900.

CARE
July 2008
53 Romney Street
London
SW1P 3RF