

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.

Christian Medical Fellowship

Introduction

The Christian Medical Fellowship (CMF) is an interdenominational organisation with more than 4,000 British doctors as members. All are Christians who desire their professional and personal lives to be governed by the Christian faith as revealed in the Bible. Members practise in all branches of the profession, and through the International Christian Medical and Dental Association are linked with like-minded colleagues in over 100 other countries.

CMF regularly makes submissions on ethical and professional matters to Government committees and official bodies. All submissions are on our website.ⁱ A number of our members will have made responses to this consultation in their professional capacities. This corporate submission, produced after consulting some members with particular experience and expertise in this field, will mainly emphasise general principles arising from our Christian commitment, though where appropriate we will make more detailed responses.

General considerations

One of CMF's aims is 'to promote Christian values, especially in bioethics and healthcare, among doctors and medical students, in the church and in society'. The 'Christian values' especially relevant to caring for those with dementia mainly concern the nature of humanity, and human relationships and responsibilities. What is the status of the person with dementia? What are the obligations of those who care for them? And what is the nature of the relationship between sufferer and carer?

The status of the person with dementia

The Christian faith teaches very clearly that unlike the animals, man and woman alone are made 'in the image of God'.ⁱⁱ Further, God ennobled each and every human being when he became incarnate in human form as Jesus Christ,ⁱⁱⁱ whose sacrificial death for the redemption of believers underlines the significance of each and every human being.^{iv} These unique characteristics of human beings are independent of any attributes possessed by the person, and therefore all human beings are always of equal intrinsic value.

We thus particularly reject any concept that human 'personhood' requires the capacity to relate meaningfully to other humans. No matter how reduced or even absent that capacity may be, the person in question is still infinitely valuable and God still has a relationship with them, even if they have no (observable) relationship with God or with other humans. Loss of memory or of cognitive ability does not rob us of our essential humanity.

The responsibilities of carers

We think it is helpful to distinguish between 'informal' carers (relatives and others) and professional staff and services. The two are distinct but need to work in partnership. Further, the professional sector also has a duty of care to the informal carer, which can partly be met by passing on appropriate skills.

It may be that some aspects of dementia care regarded as 'ethical' (perhaps in the areas of communication and operational decision-making) are more matters of professional competence and skill and the best application of service resources than they are primarily and intrinsically 'ethical'. Some specialists, particularly Registered Mental Nurses, who are skilled at communicating with and managing advanced dementia sufferers, show remarkable finesse when reconciling truth-telling with personal day-to-day case management so that ethical dilemmas such as the use of restraint become less common.

When considering the usual ethical principles, such as the 'philosophical medical ethics' rules of 'autonomy-beneficence-non-maleficence-justice', the whole area of dementia care is a 'hard case' and hard cases make bad law. Normative frameworks, guidelines and law may not adequately answer all dilemmas in dementia care, and particularly for informal carers, 'virtue ethics' – those arising from the character of the carer – thus become increasingly appropriate.

The best response to apparently irresolvable dilemmas comes from the wise judgement of a mature and reflective person who is motivated by concern for the other's welfare. Such a person will acknowledge guidelines but perhaps not always be ruled by them. Such a person will recognise the possibility that they may have conflicting motives concerning any particular decision. In healthy families and other close relationships, the 'virtuous' carer acts out of love.

The relationship between people with dementia and their carers

Dementia patients are often seen as having become 'lost' and unable to express their former selves, and their carers may feel unable to work out how to relate to them. However, the person is still 'there' even though increasingly difficult to access and communicate with. Communication may come and go and it is important to seize opportunities when they arise.

People with dementia may be seen solely as recipients of care, but in fact they can continue to contribute in different ways to those who care for them. Care of people with dementia enriches society and the caring relationship remains two way right up until death. Dementia is not purely negative; there can be opportunities for personal growth, development, learning, and the enhancement of relationships for both the person with dementia and their carers.

The general approach to difficult decisions

Acknowledging the intrinsic moral value of the person with dementia, and the carers' obligation to act virtuously and with skill, hard decisions should therefore normally be taken after reflective discussion between concerned parties. If there remain conflicting views, relevant authority figures such as senior health professionals or lawyers should be involved.

What is dementia and how is it experienced?

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?

For the person with dementia, anxiety and fear have the greatest impact, accompanied by grief from slow, progressive loss. For families and carers, there is an ambiguous sense of loss and fear of the future burden of care. We are concerned that for society, current publicity given to the possible size of the future economic problem, while necessary and appropriate, may fuel an atmosphere of fear and rejection.

As a priority, informal carers need reliably available, expert back-up from health and social services, who must work in close partnership with each other. Current controversies about funding medication have perhaps raised unrealistic hopes and detracted from the central priorities of social care and support with medical back-up for managing acute intercurrent illnesses.

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

Members working in the field report:

- Control of dysfunctional behaviour, by restraint or medication

- Covert administration of medication

- Use of antipsychotic medication, which even if harmful can be justified if it reduces distress felt by the patient and increases their comfort

- Using the patient's own money, without their consent, to pay for their care

Processes designed to protect people with dementia from abuse can actually obstruct the care they need – form-filling detracts from care and some treatments can be missed out (for example, flu vaccines in some Scottish care homes were not given because of the bureaucracy involved under the Scottish Act).

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?

Within any one ethnic group, the understanding of dementia varies from denial, through incomprehension to an informed acceptance of reality. There are no difficulties unique to any one ethnic group.

However, groups already disadvantaged may expect less and demand less. Some ethnic groups simply find it more difficult to engage with services and to trust providers.

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

One doctor reports that the 'white British' group seems especially unable to provide family support, where other ethnic groups do better; another expert does not share that experience. Another reports that assumptions about institutional care are not usually correct in South Asian communities.

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?

All avenues that increase understanding and that may lead to more effective diagnosis and to more effective treatments are significant.

However, the fundamental issue remains to promote innovative care strategies to enable better care in the person's home and in care homes.

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?

Those we consulted expressed a range of views. A GP said: '...early diagnosis seems to me to be unhelpful unless specific intervention or support would be likely to be of overall benefit at the point in question. Many people and families accept a certain amount of early cognitive decline as a "normal" part of ageing. Definitive diagnosis of dementia is normally only appropriate when the reasonable tolerance of symptoms by the individual and their family is becoming challenged.'

An experienced consultant said: 'As soon as it can be confidently made and there is no risk of over-burdening the individual and their family with potentially inaccurate information'.

Another consultant was more positive about early diagnosis: 'Early diagnosis is helpful as it gives the opportunity of early treatment and modification of cardiovascular risk factors. What is important is that *diagnosis is discussed and misunderstandings allayed*. This can provide a huge opportunity and the existence of some treatments is a practical help, as it will lighten the emotional blow. A partially treatable illness is much less of a blow than an untreatable one and dementia has moved from the untreatable to the treatable in the last decade.'

Perhaps at the centre of this range of views is the importance of good communication, particularly to overcome the risk of stigmatisation.

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?

Society is afraid of dementia; fails to see what can be done for it; and fails to see the contribution people with dementia make. This contribution includes their funding of care, thus creating employment; and their enriching families and

society. It is important to try to persuade the population that people with dementia enrich society, and we should facilitate ways in which society can experience this enrichment. The media could provide much more positive modelling.

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

Stigma often delays the initial process of seeking a diagnosis – for example, in spouse concealment. Thereafter it plays only a small part, since by the time definitive diagnosis is made the facts can no longer be denied or concealed.

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

For those with early or mild dementia, sensitive inclusion within the everyday life of communities can be helpful as it improves their quality of life. At this level, people with dementia should be treated the same as those with other serious physical illnesses.

For those with more severe dementia, where behavioural sequelae are more difficult to manage, and their level of awareness and their consequent ability to benefit from inclusion is more limited, the decision becomes one of balancing those matters against the benefits of raising public understanding and counteracting prejudice.

So, while the primary concern should be for the person with dementia, a secondary issue is that more inclusion of those with dementia would reduce stigma.

Person-centred care and personal identity

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

Yes. We support the Christian concept that we are ‘physical, emotional, social and spiritual beings’. It is always helpful to have the person’s whole identity uppermost in the minds of all those involved. It improves the quality of relationship, and enables all concerned to see the person in context. This may help the person with dementia to function at a higher level.

However, while voicing strong support for ‘person-centred’ care we would not want to reinforce any false dichotomy between medical models and more ‘personalised’ care. As well as being appropriately skilled in their disciplines, professionals should practise person-centred care at all times.

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

Dementia changes roles but not identity. It is the same person who in old age has advanced dementia, but who when younger was healthy in body and mind. There is some discontinuity, but not complete discontinuity. All persons remain of inherent worth and dignity throughout the whole span of their life, known to God, no matter what changes may have taken place.

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?

Sadly, such changes can be destructive, but they occur in the context of illness and need to be understood as such. The onset of illness changes, if not previous commitments themselves, then the application of broad commitments made earlier. 'We promised we would never put mum in a home' can lead to aberrant decision making that puts other family members at risk. We should have at heart a holistic view of the best interests of the person with dementia, and secondarily, of those close to them.

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?

The person's previous world view should be taken into account – their spiritual world, their moral values, their artistic and cultural preferences; but answering how that previous world view balances their (apparent) wishes in their current situation requires an element of human judgment. That judgment therefore needs to be strengthened by as holistic a picture of the person's best interest as is possible, with the emphasis being more towards the present than the past. Such a judgment is normally best made by those with an ongoing knowledge and concern for the person involved, so long as personal confounding interests can be identified and excluded.

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

It would largely depend on the nature and extent of any risks involved. We should play it safe to the extent that the person themselves and others are protected. For example, if in doubt, financial decisions should be made for them so that they cannot be defrauded.

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

The concepts of patient-centred and palliative care are particularly necessary here.

Recognising that every case is unique, decisions about life-sustaining treatment always relate to the context of the life as it is experienced and as it may reasonably be expected to be in the future. A holistic picture of reasonable life expectations and the degree to which treatment is routine or 'heroic' would all have a place when considering life-sustaining treatments.

But, given that advanced dementia is a terminal illness and one which is associated for some with considerable suffering, it may be right and proper to recognise that the natural end of life may be drawing near, so that life-sustaining treatments need not always be given. The total situation must be considered, not the diagnosis of dementia *per se*.

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?

One experienced consultant writes: 'well qualified welfare attorneys can be helpful but those simply "on a mission" are usually unhelpful. There needs to be a clearly demarcated route for disagreements to go to arbitration quickly.'

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?

Advance directives should be respected as a clear statement of the patient's wishes *at the time that the directive was made*. This will normally be highly relevant in the holistic consideration of a patient's best interest, but cannot be the sole determinant if strong counter arguments can be made that the patient's priorities and desires have self evidently changed. The criteria for invalidity in the Mental Capacity Act may be very helpful at times of doubt.

Properly applied, advance directives can considerably relieve pressure on families, who may otherwise carry an unnecessary burden of guilt for non-treatment decisions.

The possibility of making advance directives should be raised with people in the early stages of dementia, while they still have capacity, but pressure should not be put on people to prepare them.

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?

One consultant writes that they have made management: 'more labour intensive but probably more realistic. IMCAs have made life difficult; they add another, often poorly accessible, link into the chain of care.'

One contributor to this response was told recently by a senior manager in Social Services that the MCA has forced us to take more risks in the community and stopped us providing the care we ought to for some people. The Scottish Act led to difficulties in providing medical care such as flu vaccines, and guidance had to be changed.

We must support professionals and carers in providing the best care for those with dementia, and allow them to do it efficiently and effectively. Sadly, if cumbersome safeguards with longwinded paperwork have to be applied before treatment is given, then treatment will sometimes not be given. Conversely, a lack of safeguards may allow abuse, although it is not properly clear that safeguards actually stop abuse.

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?

The Judeo-Christian tradition has always endorsed truth telling, from the Commandment 'You shall not give false testimony against your neighbour' onwards.v However, there are rare but well recognised exceptions when deception is supported (Hebrew midwives disobeyed an Egyptian command to kill Hebrew baby boys at birth and lied about it,vi and Rahab hid Hebrew spies and liedvii).

There may thus be occasional cases when evasion or distraction are permissible. The central concept would be the intention behind the deception: is it just for my convenience (the carer)? Or does it have the patient's best interests at heart, in diverting them from a troublesome concern? This question is partly about expertise in communication and the professional-patient relationship.

One consultant gives the following example: A person with dementia cannot leave the institution because of their disability but keeps asking to go home. Options for response are:

- 1 No, because you have dementia and are incapable
- 2 We cannot manage that today but we can think about it
- 3 Not at present, but if ever you are well enough we will want you to go home
- 4 Yes, tomorrow

Only answer 4 is a lie and is probably the worst option, because to silence the enquirer temporarily it deliberately and cruelly deceives them for the future.

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?

Generally, carers tend to err too much on the side of caution when considering behaviours that involve a degree of risk but may also confer a degree of benefit on a person with dementia. One contributor commented that there is inconsistency when time and effort is spent protecting rights and identity, but people are allowed to wander around and fall, or get lost in the community.

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?

The key issues are recognising the presence or absence of autonomy, and the issue of best interests. In advanced dementia meaningful autonomy may be impossible in many situations but still possible in others – hence the issue of capacity for specific tasks. Restraint should not be excluded when there is a genuinely compelling need relating to the patient's safety or the safety of others. However, restraint should not be seen as a means of ensuring convenience for carers, or for staff in care facilities.

Historically the use of restraint of various kinds has often been an alibi for inadequate staffing levels and poor clinical practice. This should not be condoned. The best examples of environmental management and astute nursing care are associated with minimal use of restraint. Ethical professionals should not collude with unethical and second best solutions caused by inadequate resources, but should campaign for more resources.

However, restraint remains an occasionally necessary component of good care. In dementia, restraint in the sense of limiting autonomy may appear in different forms: locking doors, giving treatment to reduce aggression and harm to others, giving antibiotics and other treatments in the face of resistance, restricting who people may see, and removing money to prevent it being stolen.

The key justification for 'restraint' is harm to the individual, and is an interesting issue with regard to the use of antipsychotic medication in dementia. These are often seen as sedatives or chemical restraint, and if they are used solely as such their use is rightly questioned. But there is also a high level of severe distress in dementia and high levels of psychosis which often drive behaviour disturbance. So if antipsychotic medicines are the best way to reduce distress in an individual with dementia, are they justified by that gain despite the known risks of harm? This is the palliative care argument. If suffering is great, it must be right that alleviating suffering takes primacy over avoiding treatments that risk harm or shortening of life.

Finally, covert medication must be seen as a form of restraint. This can be justified if the treatment cannot be provided in a less restrictive way and if harm is avoided; the benefit being proportionate to the infringement of liberty.

Pharmaceutical restraint is an especially difficult issue, but is not different in principle from other forms of restraint. It may occasionally be justified as a means of enabling a carer to keep a patient at home where this benefits the patient and where significant harm would otherwise occur, but a positive guard against prescribing for convenience must always be maintained.

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?

Yes, though we question again whether the 'ethical aspects' actually come down to professionalism and skills. Perhaps the most important principle is to help people see that much of the care provided is, in effect, palliative. The principles of palliative care are very useful here:

- Cherishing life – 'You matter because you are you'
- Accepting natural death
- Enabling and improving where possible – maximising autonomy
- Seeing distress as key and more important than individual clinical outcomes
- Treating to improve quality of life ahead of automatically prolonging it
- Helping people to live before they die

If these principles were consciously applied to people with dementia, perhaps those who care for them would be better able to understand the reasons why they do what they do. Providing the best possible holistic care, while limiting care that is burdensome, might help to develop a culture within dementia care that has worked so well in palliative care.

However, while the palliative care parallel is of value, old-age psychiatry is different. Dementia is generally longer term than 'dying' and dementia care needs its own scales of objectives and performance outcome criteria. It is a challenge to the professions and disciplines involved to develop these, in partnership where appropriate with informal carers.

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?

New technologies that help maintain independence are to be welcomed. To the extent that they protect the person and are used in their best interest, they should be used with people's assent. Sometimes however, they can be giving carers a false sense of reassurance without providing the comfort and support that those with dementia really need. Technologies themselves are no substitute for expertise.

They are not used more because of a lack of clarity about our duty of care, and because budgets for such equipment are small.

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

The state should see those with dementia as citizens of as equal intrinsic worth as any other, but who face particular challenges of living with dignity. The state should also recognise the exceptional demands often placed upon family and other carers. Within this framework the state should then allocate resources fairly to this group of patients and carers as to any other group, considering the respective degree of need of each.

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?

Typically these revolve around the family home and the financial assets of the person with dementia, alongside the burden of care placed on the family if the person continues to live in the community. The person with dementia must be considered as a vulnerable adult and their needs considered first. Respite care can be risky for the patient but good for the carer. Reliably available professional back-up should always be there, for example to manage acute intercurrent medical problems and their added social stresses.

Q26 What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

The 'going into a home' debate needs to be resolved by an honest reappraisal of any previous commitments, by considering all the options, and by considering what harm will be reduced by the 'restraint' of institutional care. Health and social care professionals are central to brokering such discussions as well as to checking the implementation of such decisions.

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?

As stated in the answer to Q26, the role of health and social care professionals is to broker discussions, seeking if possible to negotiate towards outcomes where the best interests of the patient are synonymous with those of the family. It is not to make judgments.

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?

An experienced consultant writes: 'Confidentiality is always a tricky thing but we generally think that there is too much of it. When a person has dementia, sharing information with relevant people will normally improve care for the person with dementia. Sometimes it will not and in such circumstances (eg a difficult relative, etc) it ought to be withheld.'

Research

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

Research should be establishing treatable causes of dementia, and finding treatments. It should also concentrate on symptom control, and on better management tools for people with dementia and their carers.

Research should cover the spectrum from the laboratory to the community, from identifying disease-modifying agents in Alzheimer's disease to agreeing clinical outcome measures and their application. The current evidence base in all these areas is inadequate.

Q30 What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

In early dementia a patient may well retain the capacity to consent to straightforward research projects in the normal way, but with carers or other guardians ensuring more complex issues of best interests are taken into account.

We are divided about whether people with more advanced dementia may ethically be included in research, other than in therapeutic studies that have a significant chance of benefiting them directly, or in non-invasive observational measures designed to define optimal strategies for nursing care or environmental support, when proxy consent might be reasonable. Some feel that if a relevant question can be answered in no other way, and the research presents no risk of harm to the person with dementia, it could proceed if there is assent. A better evidence base is essential, but must be obtained ethically.

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?

We are not aware of relevant research being prevented by the current legislative framework. The present arrangements are adequate for safeguarding patients but sometimes make the task of performing research arduous. There needs to be a new approach to performing research that takes into account the impossibility of obtaining informed consent. One contributor believes 'assent as a legal means of proceeding within strict external safeguards would be useful'.

Other issues

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

Feeding and nutrition

Advanced dementia is effectively a terminal illness and this should be borne in mind by all concerned when withholding and withdrawing life-prolonging treatment and providing artificial nutrition and hydration are being considered. CMF has set out its position on the difficult question of artificial nutrition and hydration in a 2001 submission to a General Medical Council consultation.viii However, the ordinary provision of nutrition can also be a cause for concern. The number of incidents related to poor nutritional care which were reported by NHS staff has almost doubled over three years.ix Many nurses responding to a Royal College of Nursing questionnaire said that they simply did not have enough time in their day to oversee the feeding and hydration of all patients who were unable to feed themselves. We suspect this issue also arises in some care homes. Recognising that patients with advancing dementia may not want to eat and drink, nevertheless we hold that every effort should be made to spend time with them to encourage them to eat and drink. This is a basic duty of care which must not be neglected.

Use of harmful treatments to alleviate suffering

Some treatments routinely given to people with dementia are harmful. The best example here is antipsychotic medication which has a sad history of being abused in dementia care. Antipsychotics increase the risks of strokes, falls and death as well as causing sedation. Such prescribing usually reflects poor care, institutional practice and habit, and inadequate staffing levels, but there can occasionally be positive, ethical reasons for using such drugs.

Dementia is associated with distress and also with psychosis. These drugs do appear effective for some in these circumstances, while for others they do not help. They are generally considered for the treatment of psychosis or BPSD (behavioural and psychological symptoms of dementia). Antipsychotics are routinely used to reduce distress in people who are dying and care pathways used in such circumstances (such as the Liverpool Care Pathway) recommend that they are at least written up as required.

It could be argued that while treatments may have an evidence base for use in specific symptoms, such as psychosis or BPSD, the evidence base alone may not justify their use. If a person is psychotic or wandering or hitting others, it

may be that that behaviour does not distress the individual and they are better left untreated. But if the patient is experiencing significant and severe distress, and the treatment is the best way to reduce that distress, then use is justified ethically. This reflects practice in palliative care, where treatments are indicated if they improve quality of life, but not if they do not.

The All Party Parliamentary Group report on antipsychotics in dementia acknowledged this view as valid.^x Were such an approach taken we suspect that prescriptions would fall but not stop, and that treatments would be better focused and justified as a result. CMF supports rigorous review in this area and notes there is an accumulating evidence base.

Pathways for the dying

When people are dying imminently their symptoms ought to be controlled and good care provided. But diagnosing imminent death may be more difficult in advanced dementia than in other conditions. The Liverpool Care Pathway is set out as the model of practice for those who are imminently dying as a result of dementia, but at present, there are difficulties with it. The criteria for diagnosing dying do not appear to be realisable in dementia, and there may be confusion among clinicians about when invoking the Pathway is indicated. Moreover, the absence of any prompt to consider the provision of oral nutrition and hydration is of ethical concern.

Particularly when treatments risk shortening life, it is very important that such treatments are given for actual symptoms. If such treatments are given in anticipation of possible symptoms, before they are actually happening, there must be concern. Inappropriately early use of sedatives, orally or by syringe drivers, must be avoided. They may be used when indicated but not before.^{xi}

Spiritual care in dementia

Although not an 'ethical' issue, there is a growing body of understanding within chaplaincy of the spiritual needs of people with dementia and of ministry to those needs.^{xii} We encourage development of this ministry at the interface of health, social and spiritual care.

Conclusion

To the secular world dementia can be seen as entirely negative, destructive, and hopeless. As Christians we believe there can be redemptive aspects to dementia. By God's grace it is possible for good to come out of evil, and the challenge to us all is to find and develop practical illustrations of this.

Christian Medical Fellowship is grateful for the opportunity to make this submission, wishes the Nuffield Council on Bioethics well in its deliberations, and is willing to help further if requested.

References

- i www.cmf.org.uk/ethics/submissions/
- ii Genesis 1:26-27

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iv eg John 3:16
v Exodus 20:16
vi Exodus 1:15-22
vii Joshua 2:1-21; Hebrews 11:31
viii <http://www.cmf.org.uk/ethics/submissions/?id=19>
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