

Assisted Dying

General Assembly 2007

RESOLUTION 51

Assisted Dying

General Assembly affirms the report Assisted Dying, as encapsulated in the following statements:

- i) As Christians we regard all human life as being God given, and therefore precious; we believe that death is not the end and we have faith that there is a more perfect life to follow.
- ii) We recognise that there is a time to die and that there are circumstances in which it will be wrong to continue to provide treatment designed to prolong life.
- iii) We recognise that some palliative treatment for the terminally ill, makes the patient more comfortable and pain free, but can also hasten death. We believe this to be acceptable, as long as the primary purpose of the treatment is pain relief and comfort of the patient.
- iv) We could not support legislation that would empower medical staff to intervene in ways which deliberately seek to assist a patient to die. We would therefore oppose any change in the law to permit voluntary euthanasia or assisted suicide.
- v) We believe that a Living Will or Advance Directive which has been prepared by a patient of sound mind, can be helpful for carers and relatives; however we do not believe such a document should be used to facilitate a person's death.
- vi) We believe that additional resources are needed to provide more uniformly available and more high quality palliative care.
- vii) We recognise the valuable contribution made by carers. We express our prayerful support for those who work in, and promote hospices, and others who care, befriend and provide support for the dying.

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A booklet containing the Paper and the Guide, in a more accessible format, will be available soon after General Assembly. We hope that it will prove to be a valuable resource for church groups. Enquiries to Church and Society church.society@urc.org.uk or 86 Tavistock Place, London WC1H 9RT.

1. Why this debate now?

1.1 The context is a momentum for change to the legislation governing euthanasia, which saw Lord Joffe's *Assisted Dying for the Terminally Ill Bill* attract considerable support in the House of Lords early in 2006. The Bill was eventually defeated, due in part to opposition from Church of England bishops sitting in the Lords, but there will almost certainly be fresh attempts to amend the law. Some Christian denominations have clearly stated positions on Assisted Dying and Euthanasia; however, these issues have not been formally discussed by the United Reformed Church. A resource pack *A Time To Die* produced by Church and Society in 2002 covered issues of bereavement and loss but deliberately made no reference to assisted suicide, for the reason that: *euthanasia is at present not legal in this country* ⁽¹⁾.

1.2 The Church and Society committee agreed in January 2006 that this was an issue that the Church should be encouraged to consider and the intention to mount a debate was signalled in the report to General Assembly in 2006 ⁽²⁾. The Committee has encouraged discussion through:

- A questionnaire, distributed widely and available at General Assembly 2006. (Section 9 and Appendix A);
- The Church and Society network hotline;
- The Church and Society pages on the URC website;
- An article in the October 2006 edition of Reform; and
- The Secretary raising the issue during visits to synods, districts and local churches;
- A study guide.

1.3 Many responded, their views nearly always being based upon formative personal experiences, either as a professional carer, or as a result of living through the death of a loved one. Encouragingly, some churches and districts reported that they held discussions, often led by people who had briefed themselves for the task. Invariably, the report back was that the debate was lively, with people sharing a range of experiences. By February 2007, 139 responses had been received, including 12 from groups. Trends from the responses are highlighted in Section 9; the questions asked and a fuller summary of responses will be found in Appendix A.

1.4 This paper does *not* pretend to be exhaustive, nor overly academic; it does try to identify the main issues of concern, recognising that medical advances make this a complex issue. It points the reader wanting more to further sources of information. In compiling it, the Church and Society Committee has been assisted particularly by the Revd Delia Bond, co-ordinator of the URC Health and Healing Network; the Revd Dr Neil Messer, senior lecturer in Christian theology in the Department of Theology and Religious Studies, University of Wales, Lampeter; Malcolm Johnson, Professor of Health and Social Policy at Bristol University, Professor of Gerontology and End of Life Care, University of Bath, and former Convener of the Church and Society Committee; Dr Pamela Cressey, Convener of Eastern Synod Church and Society Committee and a retired GP, and colleague members of the Methodist, Baptist and United Reformed Church Joint Public Issues Team; and also by the many people who have taken the trouble to respond to the questionnaire (See Section 9 and Appendix A).

2. Political context

2.1 Lord Joffe's Bill would have enabled adults of sound mind, who were suffering unbearably as a result of terminal illness, to receive medical assistance to die at their own request ⁽³⁾. The Bill contained a number of safeguards, including requiring that:

There be medical confirmation that the person was of sound mind, had a terminal illness, and was suffering unbearably;
A specialist in palliative care discuss other options with the patient;
A second doctor confirm the diagnosis;
A solicitor and an unbiased witness satisfy themselves that the criteria had been fulfilled;
The patient be given fourteen days to change her/his mind.

2.2 The Bill was defeated by 148 votes to 100 after a seven hour debate. The Archbishop of Canterbury was one of those who spoke against it, saying:

Whether or not you believe that God enters into consideration, it remains true that to specify, even in the fairly broad terms of the Bill, conditions under which it would be both reasonable and legal to end your life, is to say that certain kinds of human life are not worth living ⁽⁴⁾.

3. Perspectives

3.1 As Christians, our perspectives on Assisted Dying, are shaped by our faith and informed by Christian theology. We acknowledge that those of other faiths, or without faith, may have a different view, informed by their background. As Christians we believe in the sanctity of human life. It is God given and not ours to extinguish. We also accept that we are mortal, and have a finite life span on earth. We believe in life after death and the promise of eternal life. There is a sense in which death is the ultimate healing. We believe in living the Christian life in all its fullness within the limitations of our circumstances.

3.2 Some Christians hold the view that life should be preserved for as long as possible, because it is always possible that God will intervene and effect a miraculous recovery, beyond that which medical science can comprehend. Others feel that whilst it could never be acceptable to help end the life of a patient by a deliberate act, in some circumstances it could be acceptable to withhold treatment and to allow a patient to die. The words of the 19th Century humanist poet Arthur Hugh Clough, are often quoted in euthanasia debates: *Thou shalt not kill, but needst not strive, officiously to keep alive* ⁽⁵⁾. These words now have a significance beyond that envisaged when Clough wrote them, for advances in medical science mean that life can be sustained, even in 'a persistent vegetative state' in patients who would have died less than a generation ago. However, it is the active provision of assistance to a patient to take her/his own life that is at issue now.

3.3 The Catholic Bishops of England and Wales and the Church of England House of Bishops submitted a joint paper to the House of Lords Select Committee formed to consider Lord Joffe's Bill. The submission was based upon the belief that God himself had given to humankind the gift of life. As such, it was to be revered and cherished. All human beings were to be valued, irrespective of – among other factors – age and potential for achievement.

3.4 The two Churches submitted that all decisions about individual lives bear upon others, with whom we live in community, and for this reason it could not be held that the law relating to euthanasia was simply concerned with private morality. This was an issue in which society had to make a positive choice to protect the interests of its vulnerable members, even if this meant limiting the freedom of determination of others.

3.5 Neither Church insisted that a dying or seriously ill person should be kept alive by all possible means for as long as possible. Patients might reasonably refuse a particular treatment as being too burdensome. Treatment for a dying patient should be proportionate to the therapeutic effect to be expected and should not be disproportionately painful, intrusive, risky, or costly, in the circumstances pertaining. Having said that, the aim of giving or refusing treatment should never be to make the patient die. Patients should not be able to demand that doctors collaborate in bringing about their death; that, the submission said, would be illegal and morally wrong. If doctors were allowed, in some circumstances, to kill their patients rather than care for them, this would lead, inexorably, to an undermining of trust. A change in the law to permit assisted dying would change the cultural air breathed by all of us, and affect attitudes to older people and those with chronic illness. The submission concluded:

It is deeply misguided to propose a law by which it would be legal for terminally ill people to be killed or assisted in suicide by those caring for them, even if there are safeguards to ensure it is only the terminally ill who would qualify. To take this step would fundamentally undermine the basis of law and medicine and undermine the duty of the state to care for vulnerable people. It would risk a gradual erosion of values in which, over time, the cold calculation of costs of caring properly for the ill and the old would loom large. As a result, many who are ill or dying would feel a burden to others. The right to die would become a duty to die ⁽⁶⁾.

3.6 The Methodist Church made a submission recognising that there were complex moral problems integral to the final stages of some terminal illnesses, but noting that the Christian tradition insists on the infinite respect owed to every individual human being – not proportional to well being, nor any assessment of seriousness of illness, injury or disability ⁽⁷⁾.

3.7 The submission of the Voluntary Euthanasia Society (now Dignity in Dying) said that many terminally ill people would like medical help to die, but to provide that help was currently illegal. Despite this, health professionals repeatedly broke the law, out of compassion and respect for the wishes of terminally ill patients. Some patients attempted to end their own life – with or without the help of a loved one – sometimes with deeply distressing consequences, not just for the patient, but also for the relative. The general public had made it clear in opinion polls that they wanted the law changed. The Society said:

the choice is not between permitting and preventing medically assisted dying. The choice is between making medically assisted dying visible and regulated, or allowing it to continue 'underground' without any safeguards, transparency or accountability ⁽⁸⁾.

Alice died two years after she was diagnosed with ovarian cancer. During the two years, she threw herself into work at her church. Her husband said: "Alice recognised she would have a short life, but she had the peace that the Lord had saved her. It was comforting for me to see her so at ease. The last thing she said to me was 'I am content' ".

*Baptist Times
20 October 2005*

3.8 The Royal College of General Practitioners opposed the Bill. The Royal College of Physicians asked its members for their views and reported that 73 per cent of those who responded were opposed to it. The British Medical Association adopted a “neutral” position, but has since said that it does not believe patients have a right to assistance to end their lives.

4. A Reformed view – by Neil Messer

4.1 There are probably four areas of debate that require some critical attention from a Christian perspective that regards ‘the Word of God in the Old and New Testaments, discerned under the guidance of the Holy Spirit, [as] the supreme authority for the faith and conduct of all God’s people’⁽⁹⁾: human autonomy; suffering, compassion and the love of neighbour; acts, omissions and the doctrine of ‘double effect’; and consequences and ‘slippery slopes’.

4.2 *Human autonomy*

4.2.1 The notion that human autonomy must be respected is a very widespread assumption in contemporary debates about medical ethics. It has philosophical roots in the work of two very different thinkers, Immanuel Kant and John Stuart Mill; Kant particularly could support a more nuanced version of it than the one frequently put about in discussions on medical ethics. Be that as it may, when respect for autonomy is considered in contemporary debates – including those about assisted dying – it often means: if I am an adult whose capacity for free and informed decision-making is not significantly impaired by illness, disability, coercion or anything else, then I should be free to do what I choose with my own life, to the extent that exercise of my freedom does not hinder anyone else’s exercise of theirs. The freedom to which I am entitled is often taken to include the freedom to end my own life at a time, and in a manner, of my own choosing and the right to seek medical help to do so. Such an understanding of autonomy informed many of the arguments in favour of the Joffe Bill, including a number of the submissions to the House of Lords Select Committee.

4.2.2 Such a view of autonomy is open to criticism from several perspectives. For example, some feminists might argue that it assumes an individualistic understanding of human life that reflects male more than female experience⁽¹⁰⁾.

From a Reformed Christian standpoint, the basic assumption that my life is my own, to do with as I choose, seems unsustainable. A key biblical theme is that God is the creator, owner and giver of human life, and no human can claim absolute ownership of their own – or anyone else’s – life. This would seem to be part of what underpins some of the laws in the Torah, including those about the taking of life. The central reason for Christians saying that ‘we are not our own’ is that we ‘were bought with a price’ (1 Cor 6: 20), that we have been ‘purchased’ by Christ’s saving death in order

Anne, a retired doctor, was suffering from an incurable brain disease. She had seen her husband die from a closely related degenerative illness, four years before. She said she did not want the “long slow demise” that he had suffered. She travelled to Switzerland to take her life, by drinking barbiturates, with the help of the Dignitas clinic. Her son said: “She was ready to go and that makes it all the easier for us. We respect her choice. We are very thankful that her suffering was over”.

*Daily Telegraph
25 January 2006*

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that our lives might be transformed, renewed and might become all that God means them to be. As Paul recognises, this affirmation sets limits on the things that we ought to do with our own – or other people's – bodies. Some might say that Paul is only addressing Christians when he says this. However, it would seem a strange theological stance to say that whatever Christ's death shows us about God's good purposes for human life *only* applies to those who are already Christians.

4.2.3 In short, if Christians are to think about euthanasia and assisted suicide, respect for autonomy will prove a very unsatisfactory starting point. A more promising start can be made from considering how God's gift of life should be respected and protected in these circumstances, or as Barth formulated it in *Church Dogmatics* what it means in these circumstances to obey the command 'Thou shalt not kill' ⁽¹¹⁾. Whereas Barth thought that obedience to God's command could, in some exceptional situations, involve the taking of human life, he seems not to have allowed that euthanasia could ever be commanded by God. Christians working within this tradition who wish to make a case for assisted dying would need to show that Barth was wrong, and that assisted suicide and euthanasia could in some circumstances be ways of obeying God's command to protect human life.

4.3 *Suffering, compassion and love of neighbour*

4.3.1 Another dominant line of argument focuses on compassion; some patients, particularly some who are chronically or terminally ill, experience terrible pain and suffering and long for death to release them; surely the compassionate thing to do is to help them to a quick, painless and dignified end. In the debate about the Joffe Bill, this view was expressed frequently and forcefully, with the help of powerful and well-publicised stories of sufferers and their families.

4.3.2 It might seem that the Christian imperative to love our neighbour as ourselves would reinforce this line of argument (as Malcolm Johnson suggest in Section 6). Those who have not experienced such suffering in their own lives or those of loved ones should be cautious in what they say about this; it would be easy to speak glibly or even callously. But that said, this line of argument contains buried assumptions that are distinctly problematic for our Christian tradition. One is the assumption that we know what 'loving our neighbour' *means*. It might seem obvious, for example, that when my neighbour is in pain, the over-riding demand of neighbour-love is to do whatever I can to relieve pain; and if that means euthanasia, so be it. But this assumption, that the relief of pain and suffering has an importance which over-rides other obligations, is a peculiarly modern one that seems to owe more to secularising trends of thought (in particular, eighteenth century utilitarianism) than to the sources of our Christian tradition. It should not be denied that the relief of suffering is a highly important obligation – the long history of Christian involvement in medicine bears witness to that – but it might not be the *only* or the *over-riding* obligation.

4.3.3 The biblical witness at the roots of our tradition suggests a more nuanced understanding of both suffering and love. For example, Paul pleaded with God to be relieved of the 'thorn in his flesh' but received the answer 'My grace is sufficient for you, for power is made perfect in weakness' (2 Cor 12:1-10), which suggests an understanding of suffering that is both richer and more complex than the utilitarian view summarised above. Certainly, in the picture presented by Paul's account, his suffering is a real and terrible evil; but at the same time, mysteriously, it has become an occasion by which he has experienced God's grace in a powerful way.

4.3.4 There is no room in this picture for downplaying the reality of suffering or for glib talk about its being 'good for the soul'. But Paul also witnesses to the mysterious ways in which God is encountered in the midst of suffering. His testimony suggests that it won't do to conclude that my over-riding obligation to my suffering neighbour is to do everything I can to end suffering, including killing her or him. Such a line of thought leads some Christian thinkers to argue that one of the most important contributions that Christian churches can make to the debate about euthanasia and assisted suicide is to

be the kind of communities that can give suffering human beings the resource to *endure* pain and indignity. Stories can be told of ways in which this has happened, to remarkable effect – the Christian roots of the hospice movement should be noted – but it has to be said that our churches often fail to live up to their calling in this regard. If our practice were better, our words and arguments might sound less hollow.

4.4 *Acts, omissions and double effect*

4.4.1 A third line of argument often used in favour of assisted dying is, in effect, that we already practice forms of euthanasia, so we might as well be honest and do it more efficiently and effectively. Doctors withhold or withdraw medical treatment that could prolong a patient's life, so why not give a lethal injection that will end it all more quickly and easily? Or again, doctors might give drugs with the aim of relieving pain even though they can foresee that those drugs would have the side-effect of shortening the patient's life. In doing this, they appeal to the ethical and legal principle of 'double effect' which states that an action done with a good intention (in this case, relieving pain) can sometimes be permissible even if it also results in a foreseen but unintended evil consequence (shortening the patient's life). Some advocates of assisted dying argue that these distinctions – between acts and omissions, and between intended and foreseen consequences – are false, and therefore if we accept some kinds of action (or inaction) that hasten patient death, we should be willing to go further and accept direct intentional killing.

4.4.2 These issues are more philosophical than theological. However, many of those who deny the significance of the act/omission distinction and the relevance of the 'double effect' principle assume a view of ethics in which the only relevant factor in assessing the morality of an act is its consequences. A strong case can be made that Christians are committed to a richer view of moral action. For example, we have a stake in the claim that there is an important difference between *aiming to relieve pain*, knowing that this might also hasten death, and *aiming to kill*. Part of the difference might lie in the effects that these different courses of action would have on those who performed them, and on the communities and societies that sanctioned them. It is not only the end results of actions that matter, but also the kind of people and communities we become. If I am a doctor who gets accustomed to aiming to kill some of my terminally ill patients, that could gradually make me into a different kind of person than I would be, if I restricted myself to trying to relieve their pain. Similarly, a society that became accustomed to the intentional killing of some of its terminally ill members might also gradually develop an altered moral character as a result ⁽¹²⁾.

4.5 *Consequences and slippery slopes*

Another important strand of public debate concerns the possible consequences, beneficial and harmful, of proposed legislation. Opponents of assisted dying sometimes argue that even if it could be morally justified in individual cases, the effect would be that the lives of many more innocent and vulnerable people would be placed at risk. A related claim is that even if legislation contained built-in safeguards, to permit assisted dying would set society on a 'slippery slope' which would lead eventually to widespread euthanasia, loss of respect for human life, and the loss of protection for the vulnerable. In a sense, these arguments are secondary to those already discussed. If Christians conclude on principle that it is morally unacceptable to legislate for assisted dying, the arguments about consequences and slippery slopes will be superfluous. However, they are not unimportant; the social consequences of legislation should be considered, and even if assisted dying were morally legitimate in some cases, it could still be the case that the likely harmful consequences were so great that it would be wrong to legalise it. This, however, is an argument that is likely to turn more on empirical evidence than theological considerations.

5. Practical considerations

5.1 Advances in technology and medicine give us choices that were not available even a generation ago; choices about whether we prolong life at all costs, or recognise that there is a time to die. So many considerations come into the debate: the age of the patient, the quality of life, the cost and efficacy of treatment and the patient's wish and readiness to die. There will be as many views on this subject as there are individuals, each coming with their own beliefs, traditions and experiences; some will have been uplifting; others will have been dreadful. Each patient will have a different threshold of pain, and attitude to suffering. Each will have thoughts and beliefs about death and personal fears. Health professionals will have their own views; they are often under pressure to assist terminally ill and suffering patients to end their lives – if not from the patient, then from family members.

5.2 As Christians we recognise we are made up of body, mind and spirit, and we function in relationships. There are many types of suffering, not just physical, and when addressing end of life issues we must heed the necessity to address not just physical, but also spiritual, mental and emotional needs.

5.3 Peace of mind is important at all stages of life, and especially at the time of death. This requires that there are opportunities for the patient to speak to, and pray with, someone she or he can trust, and to express concerns regarding people left behind, and the restoration of relationships, with God, family members and others. Often it is too difficult and painful to speak with those who are closest. It will be the chaplain, minister, doctor or nurse – especially in a hospice setting – who will listen, reflect and allow the patient to make confession and give thanks. These professionals who, daily, see suffering in others, have their own perspective, and also need to be supported in prayer and love.

5.4 This is an important part of the Healing Ministry. See Appendix D. As churches and individuals we pray for healing, and have to accept that sometimes the greatest healing is death and being brought into the nearer presence of God. We do see prayers answered, and we give thanks when people are cured and healed. We long for all prayers to be answered in the way we want, but have to content ourselves with the knowledge that prayers are answered by God in his time and his way.

5.5 Hospice facilities are under-resourced and there is insufficient capacity to cope with all who are terminally ill (see Section 8). Many without families die alone in hospital – not always the best place to be when dying, as hospital resources are seldom directed to give the love, understanding, spiritual and emotional care and attention required. Care in the home from specialist nursing organisations can be wonderful, if available, but if lacking, can put a great strain on families.

Superman actor Christopher Reeve was paralysed in a horse-riding accident in 1995; his spinal injury was so severe that his first lucid thought was that it might be better for everyone if he were to die. However, his passion for how he chose to live his life from then on, his courage, his determination and his generosity in spirit were an inspiration to all those he subsequently met. He died in October 2004.

*Christopher and Dana
Reeve Foundation
www.christopherreeve.org*

5.6 In recent years, people have often been reluctant to discuss death, leaving superstition, fear, anger and guilt, especially about untimely death. Many say they are not afraid of death itself, but of the manner of dying as they have seen suffering first hand. They are fearful of unmanageable pain in body, mind or spirit and of the inability to communicate wishes, and loss of dignity when they reach a point where they can do nothing for themselves. Many are afraid of dementia and the loss of personality. There is a fear of life-threatening diseases, and the treatment – or unavailability of treatment. People ask themselves: Will I be able to cope – and what about those looking after me. What about the burden I will be to them? There are those who say: If ever I become a vegetable and can no longer speak or move or do anything for myself, then please do not artificially keep me alive. What most would wish for is a timely, gentle and peaceful death in a loving, caring situation.

5.7 It is difficult to observe suffering in others, and difficult for the sufferer to endure. Where does suffering fit into the Christian perspective? We are all part of a fallen world – it is part of our human condition. There is evil, sickness, suffering and dis-ease; we cannot escape it whatever our piety and belief, none of us is immune. We are all caught up in it, until God's Kingdom comes, it will continue to be so. We believe God does not send suffering but promises to be with us in our suffering and works through channels here on earth. He works through those who are alongside, who strive to alleviate and prevent the suffering of others. The Church, God's body on earth – through prayer, pastoral care, befriending, listening and the healing ministry in its broadest sense – can reach out to those who are suffering and dying. Through being part of, or in touch with, the caring professions – reaching out into the wider community and looking at wider world issues – the Church has a significant role in the alleviation and prevention of suffering. The developing concept of "parish nursing" may come to play a significant role. See Appendix C.

5.8 As Christians we believe in the sanctity of human life, life is God given and not ours to extinguish. Equally, we have to accept that the greatest healing is death and being brought into the nearer presence of God. We also accept that we are mortal and have a finite span on earth, and that death will come to each; we are not immortal. We believe in life after death and the promise of eternal life. We believe in living the Christian life in all its fullness within the limitations of our circumstances. Our Christian lives should be manifest by showing and sharing Christian love, care and concern, and by praying for one another.

5.9 As you read this paper, this may well be a good point at which to pause – for reflection and prayer.

Our son Danny died a drawn-out, painful death from an incurable bowel disease. By the time he was 21 he had gone through over 300 operations. We pursued every possible hope until the top international specialists eventually conceded there was nothing more they could do. The best drugs often couldn't alleviate his pain and so he spent the last year of his life asking the doctors for medical help to die. The doctors would not help him die and instead Danny practically had to starve himself to death. What he went through at the end of his life is a disgrace. After all Danny had to go through, he should have at least had the choice of dying well.

*People's stories from
Dignity in Dying
www.dignityindying.org.uk*

6. A researcher's epiphany – a personal view by Malcolm Johnson

6.1 As an academic gerontologist (a researcher on ageing and the lifespan), like the overwhelming majority of other gerontologists – who study everything up to the brink, but no further – I had paid little professional attention to death and dying. But in 1988, I was asked to produce an Open University course on end of life issues. After much effort, we not only persuaded the Department of Health to fund the production, but also completed a full half-credit undergraduate course, *Death, Dying and Bereavement* which has now been used by up to 40,000 students ⁽¹³⁾.

6.2 During the three years it took to create the learning materials, the Course Team were immersed in matters related to dying. It was an immensely difficult human task; though very rewarding. We had many wonderful collaborators, including St Christopher's Hospice in South London and its charismatic founder, Dame Cicely Saunders, who is regarded as being the founder of the Modern Hospice Movement. Dame Cicely promoted the humane care of dying people with the evangelical zeal of the deeply convinced Christian she was. At that time and later, I was persuaded of her orthodox Anglican Christian view that all life was sacred and should never be taken. She added to this dictum a phrase that has become the doubtful mantra of the hospice and palliative care movement: The taking of life is never justified because we now have the ability to deal with all pain. This claim was made extensively by those who opposed Lord Joffe's Bill.

6.3 Further involvement with death and dying led me into work on funerals and memorialising with another social innovator, Lord Michael Young, who had just created The National Funerals College as a result of the misery he saw in researching his book *A Good Death* ⁽¹⁴⁾. Michael – a sometime Buddhist – observed the common everyday experience of death as a lamentable commentary on our death-denying society. We wrote (along with others) a publication called *The Dead Citizens Charter* ⁽¹⁵⁾. I took a closer interest in the real life experience of dying at the end of the 20th century, including training staff in care homes for older people, on how to understand the social and psychological processes of dying. My team taught the history of death, the cultural diversity of approaches to death and elders, the importance of symbolic rituals such as funerals, the contemporary meanings of spirituality and 'biographical pain' and how to deal with death professionals – funeral directors, doctors and clergy.

6.4 My research on older people at the end of life led me to understand the anguish that many experience as they face imminent death. The average age of people in care homes today is 90. With endless time to think, but not much time to live, a great deal of time is given over to reflection. For some, all is harmony and contentment. But most find that unconfined time for life review takes them into the deeper recesses of memory. Too often the dominant recollections are of dreadful experiences – things done by others to harm them, actions taken but deeply regretted, things always promised yet still undone. This leisure to reflect is accompanied by disability and an incapacity to right these wrongs, and there is much guilt and self loathing. Some see this as unforgivable sin. Others with no belief, simply feel tortured. Yet they rarely find a sympathetic and safe listener to relieve this profound distress: which I have called 'biographical pain'.

6.5 So when we observe the landscape of contemporary death, it is not one of pain-free transition, assisted to a comfortable end by palliative care. Such services are rationed (mostly to younger people with cancers). More to the point, the indications are that the great majority die in physical pain which goes untreated or unreached by medication; or in unrevealed 'biographical pain'. Without the opportunity to be relieved of this appalling anguish and the possibility of forgiveness, it seems right to allow those whose lives are a living hell to exit with careful provision, and dignity.

6.6 These observations over nearly a decade have made me a critical friend of the hospice movement and I am no longer able to stand with Dame Cicely Saunders on assisted death. I no longer accept arguments about the nobility of pain or the restrictions on freewill imposed by a God who will choose the hour and the manner of death, regardless of human cost. This is not our God of love. When you have seen it, you recognise the awfulness of continuing to sustain life that is finished; you know that to enable a patient to choose to leave it all behind in a controlled and honest way is a supreme act of love.

6.7 In this brief account of an emerging recognition of the fallacy of the theologically supported view that all life is worth living, there has been no space to address the theological arguments. Yet there is much to be said about the perversity of the arguments which elevate 'God-given' pain, however extreme, into an opportunity for personal growth and grace. Nor is it a repudiation of the sanctity of life argument to recognise that there are circumstances in which sustaining human life is no more than pious punishment. So, I hope the United reformed Church, and other mainstream churches in the UK, will soon come out from behind the screen of traditional but flawed theology – as we so commendably have in the case of women and homosexuals – to support humane and well-ordered policies, which will enable the tormented to end their suffering with dignity.

7. Living Wills

7.1 Provisions of the Mental Capacity Act 2005, expected to come into force in autumn 2007, put on a statutory footing – and therefore give greater status to – so-called 'Living Wills' or 'Advance Directives'. These can be used as a way to express preferences regarding health care and treatment in the event of incapacity. They allow individuals, while they are mentally able, to give expression to how they wish to be treated in certain circumstances; this information goes to their medical advisers, and if requested, to a friend or family member, who would act on their behalf if they became physically and/or mentally incapacitated.

7.2 Some see this as a helpful way in which patients can make clear their views to medical staff and relatives particularly on life sustaining treatment and resuscitation. Knowing the patient's wishes can avoid confusion and assist carers and families when difficult decisions are discussed regarding further intrusive surgery, intensive treatment and resuscitation. However, there is concern about such documents being ignored or used to *facilitate* a person's death.

7.3 Discussion with Churches – particularly with the Catholic Church – resulted in safeguards being written into the Act. One of the most significant was the statement that the default position would be to continue treatment – that is to say that if there was any doubt about the patient's intentions or state of mind when writing the Living Will, or the motives of the person appointed to act, then treatment should be continued until these were resolved.

7.4 Some fears concerning the legislation do remain: A Living Will might not give the patient adequate opportunity to change her/his mind in a situation that was not adequately foreseen, a vulnerable patient could be exposed to pressure in drawing-up a Living Will, and anyway, any such document, drawn-up in advance, could not cover all conceivable circumstances that might arise. (The Catholic Bishops Conference of England and Wales is producing a booklet on Living Wills, to be published, by the Catholic Trust Society).

7.5 An example of a Living Will can be seen in Appendix B

8. Palliative Care

8.1 Good palliative care recognises that each person has unique physical, emotional and spiritual needs, all of which ought to be addressed. It aims neither to hasten death, nor to prolong life at all costs. But accepts that when a patient is dying, the relief of suffering, be it physical, emotional or spiritual, takes precedence over both of these concerns.

8.2 There have been rapid advances in palliative care and in the growth of the hospice movement, such that a briefing by the Christian group CARE says succinctly: *We do not have to kill the patient to kill the symptoms* ⁽¹⁶⁾. However, provision and expertise is not uniformly available. There seems to be general agreement on the need for better provision and for medical staff to be better trained in the discipline – a clear point to emerge from the responses to the Church and Society Questionnaire (Section 9 and Appendix A).

9. Response to questionnaire

9.1 Church and Society highlighted a number of questions in its questionnaire. By February 2007 139 responses had been received, including 12 from groups. Trends from the responses are identified below; the questions asked and a fuller list of responses is detailed in Appendix A.

Many people are worried about becoming a burden as their health fails.

Most are not so much afraid of death itself, but have associated fears: being alone, suffering unbearable pain, and losing dignity.

Most accept that there may come a time when it is right to withdraw medical intervention, but that this is not the same as assisting the death of someone who still has quality of life.

Most accept that some palliative treatment may hasten death, and are happy with this, as long as the intention of treatment is relief of pain.

People do fear that if assisted dying is permitted, the permission may be misused.

Everyone agrees that palliative care should be better resourced.

Dependent upon a wheelchair since girlhood, **Janice** hopes her rapidly progressing muscular dystrophy won't claim her life before she has a chance to see her 17-year-old daughter go to college. Despite pain and immobility, Janice says she never would kill herself and thinks it is an awful mistake to allow doctors to prescribe life-ending drugs to people facing terminal illness. The core of Janice's belief is that life is a gift, no matter what the person's situation. Assisted suicide sends the opposite message, she believes. "If someone becomes an inconvenience or a bother, we throw them away. It's a Pandora's box. We don't have a clue about what this is going to do in the future."

www.euthanasia.com

10. Conclusion

10.1 Church and Society encourages General Assembly to recognise that Assisted Dying is a complex subject; advances in technology and medicine pose new challenges. We believe there is a time to die, and we recognise that there are circumstances in which it will be wrong to continue to provide treatment designed to prolong life. However, we do not believe it is right to empower, or to give doctors responsibility for providing, medical intervention which deliberately seeks to assist a patient to die. We recognise that these are often matters of fine judgment but we do not support changes to legislation to allow assisted dying or euthanasia.

10.2 There is clearly considerable interest in the subject within the Church. Many people have views born out of personal experience of seeing suffering in body, mind or spirit – or all three. Most have experienced the death of a loved one and that has helped form their view on death and the way of dying. Sensitivity rather than dogmatic pronouncement is therefore required.

10.3 We recognise that the issues raised have implications for the Church and the pastoral care of the chronically sick and the terminally ill. There is a need to offer prayerful support, for sufferers and carers. We recognise pain can be in body, mind and spirit, and that care must be taken to address all three.

10.4 We recognise and respect the fact that those of other faiths, or no faith, may have a different view of life, death and suffering.

10.5 Whilst acknowledging the dilemma and anxiety which sometimes surrounds terminal illness, we believe the vulnerable might be at risk from possible abuse of legislation that would empower medical staff to intervene in ways which deliberately seek to assist a patient to die. However, we do support the right that terminally ill patients already have, to decline treatment that might prolong life.

Yvonne,
had only a distant elderly cousin and was fearful about what would happen if she became terminally ill or mentally incapacitated. She wanted to make provision for that eventuality, so asked various friends and a solicitor to take care of her affairs, in that event. She approached her minister to take her funeral when the time came and gave instructions for that too. Sadly she developed cancer just a few years later, went through all the usual treatments and yet died a year later, after the expectation and hope that she would have 2-3 more years.

She died after just a few weeks in a hospice, supported by the church and surrounded by many friends who really valued her friendship and had great love for her. She was afraid of pain, and had a Living Will in place. When she knew there was no coming back, she bravely faced the inevitability of death. She prepared herself with prayers of confession, was prayed with on numerous occasions, she was anointed and found a deep peace, but would often ask: 'Is today the day when I will die. When will it be?' Other patients came into her small ward and

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occupied the other beds, and died and she was still there witnessing their deaths. Painkilling morphine helped her, but also had other side effects. She did not want to be artificially fed or to have more intrusive surgery, she was kept comfortable and pain free, but as she got weaker, she said: 'I am ready for the Lord to take me, there is no more I can do for anyone'. Over the weeks she slowly got weaker and when she died she had close friends around her.

The minister took her funeral as she had requested with her hymns and wishes adhered to. Her church was packed, with friends. The singing was great as they gave thanks for her life. She used her Living Will, died with dignity and love surrounding her, she had refused some treatment when it was no longer going to be beneficial, and was ready to die when the time came, and totally at peace with herself and her Lord and those around her.

11. References

1. United Reformed Church. *A Time to Die. A resource pack for the churches.* 2002
2. United Reformed Church. *General Assembly 2006. Annual report, resolutions and papers.* Page 52, para. 5.3.
3. *Assisted Dying for the Terminally Ill Bill.* Printed 9 November 2005. Full text available at http://www.publications.parliament.uk/pa/pabills/200506/assisted_dying_for_the_terminally_ill.htm
4. *Church Times.* 19 May 2006
5. Arthur Hugh Clough. 1819–1861
6. Catholic Bishops Conference of England and Wales and Church of England House of Bishops. *Joint submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill.* 2004. Available at <http://www.catholicchurch.org.uk/topics/euthanasia.htm> and http://www.cofe.anglican.org/news/news_item.2004-10-19.9713099720
7. Methodist Church of Great Britain. *Written response to the House of Lords Select committee on the Assisted Dying for the Terminally Ill Bill.* 2004. Available at <http://www.methodist.org.uk/index.cfm?fuseaction=news.content&cmid=915>
8. Voluntary Euthanasia Society (now Dignity in Dying). *Submission to the House of Lords select committee on the Assisted Dying for the Terminally Ill Bill.* 2004 Available at www.dignityindying.org.uk
9. United Reformed Church. The Basis of Union, Schedule D
10. Susan Frank Parsons, *Feminism and Christian Ethics,* Cambridge: Cambridge University Press, 1996, pp. 53-6, 137-41.
11. Karl Barth. *Church Dogmatics,* vol. 3 of 14.
12. Acts, omissions and double effect are helpfully dealt with by Nigel Biggar *Aiming to Kill: the ethics of suicide and euthanasia.* London: Darton, Longman & Todd. 2004
13. Donna Dickenson, Malcolm Johnson and Jeanne Katz (eds) *Death, Dying and Bereavement.* London: Sage (Second edition). 1993 & 2000
14. Michael Young and Lesley Cullen. *A Good Death: Conversations with East Londoners.* London: Routledge. 1966
15. Michael Young, Malcolm Johnson et al. *The Dead Citizens Charter: National Funerals College.* Available from NFC, 75, Long Ashton Road, Bristol, BS41 9HY, price £5. Cheques payable to National Funerals College.
16. *Euthanasia Explained.* CARE. Undated.

12. Sources of further information

The Life Valued programme of CARE, a Christian charity, opposes any change to the law regarding assisted dying for the terminally ill and supports the development of better palliative care (www.care.org.uk).

Care NOT Killing is an alliance of human rights and healthcare groups and faith-based organisations which seeks to promote better palliative care, to ensure that legislation regarding euthanasia and assisted suicide is not relaxed (www.carenotkilling.org.uk).

Not Dead Yet UK is a network of disabled people who have joined an international alliance of those who oppose the 'legalised killing' of disabled people (http://www.livingwithdignity.info/ndy_home.html).

Dignity in Dying (formerly the Voluntary Euthanasia Society) promotes patient choice at the end of life and campaigns for a change in the law to permit medically assisted dying within strict safeguards (www.dignityindying.org.uk).

Friends at the End supports doctor assisted suicide with good palliative care (www.friends-at-the-end.org.uk).

More information about **Parish Nursing** (Appendix D) (available at www.parishnursing.co.uk).

13. Suggested further reading

Report of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill. 2005. Available at www.parliament.the-stationery-office.co.uk/HL/86-I,86-II,86-III.

Report of a debate in the Scottish Parliament on 'Dying with Dignity' 11 December 2006 is at <http://www.scottish.parliament.uk/business/officialReports/meetingsParliament/or-04/sor1111-02.htm#Col11876>

Minutes of the meeting of a Scottish cross-party group on palliative care on 17 November 2004 are at http://www.scottish.parliament.uk/msp/crossPartyGroups/groups/palliative-docs/Minutes_041117.pdf

A guide to the Scottish Dying with Dignity consultation is at <http://www.scottish.parliament.uk/business/bills/pdfs/mb-consultations/DyingWithDignity-summary.pdf>

Nigel Biggar *Aiming to Kill: the ethics of suicide and euthanasia*. London: Darton, Longman & Todd, 2004.

Neil Messer *SCM Study Guide to Christian Ethics*. London: SCM 2006.

Allen Verhey *Reading the Bible in the strange world of medicine*. Grand Rapids: Eerdmans 2003.

Bert had had several heart attacks and strokes, and life was limited to a wheelchair. Conversation was difficult, and he could do nothing for himself. A life long Christian he had requested the doctors not to resuscitate him if he had another major heart attack; he had endured enough. He put his things in order with his family and friends and with God, was at peace and took every day as it came. He enjoyed life within his very limited condition, and when he suffered another massive heart attack, he died.

Appendix A

Summary of responses to questionnaire

One hundred and thirty-nine responses were received by 16 February 2007, including twelve from groups. Numbers in brackets indicates where several respondents made the same point.

1

As Christians how does our faith affect our views on this subject?

- sanctity of life/precious gift (16)
- eternal dimension affecting perspective on temporal events; death as end and beginning (19); God with us in the transition (2); helps take fear out of death (6); allows us to talk about death during life; brings hope but should acknowledge pain of loss
- gives view of suffering at odds with culture of comfort
- only God has right to end life (9) – no person should interfere; God's will, right time (5); should not act like God in extending longevity (4)
- well-being is material, physical *and* spiritual
- Christ's love for us – why does he let us suffer? God does not wish his children to suffer (3)
- my belief and desire to be allowed to make choices regarding my destiny goes against general Christian belief
- makes it very difficult to accept assisted dying (2)
- do not believe in conscious personal life 'after' death – understand eternity as another dimension – through faith we are granted windows into gift of eternal life
- not as much as it should
- very little (3)
- sometimes conflicts with more human instinct that no one should have to linger in pain, lack of dignity, burden (13)
- ensure way we live does not directly or indirectly cause death of another person
- medical advances and caring professionals, are also expressions of God's love (2)
- God's will that we should care for one another until end of life (3)
- life should not be ended prematurely or irresponsibly
- transforms it; life beyond death as an excitement to be anticipated eagerly but life on earth still sacred.

2

What is the "ideal" death?

- in faith; reconciled to God/at peace with God (8); at the end of a fulfilled life in assurance of God's forgiveness and love (3)
- without pain/anxiety (35) and loss of physical/mental dignity (11)
- anticipated; not lingering – surrounded by love, family, friends (27)
- with time of preparation (12) farewells/restoring relationships
- in sleep/peacefully (30); quick (21); when elderly/after long and fulfilled life (6)
- to die suddenly with no illness/pain – but this is selfish, a shock for relatives/friends – and why should I be so fortunate as not to suffer

- at time chosen by individual if possible (including right to have assistance to die)
- not causing too much pain for those who love me – having confidence that those we love can go on without us (4)
- peaceful cessation of the human machine
- can there be such a thing? (4).

3

Are we worried about becoming a burden, restricting the lives of carers, using up family resources, and not getting good care?

- yes to all of these (70)
- generally no (5); God will supply; trust in God's care and love; 'worry' shows our failure to trust
- media generate anxiety
- being a burden/restricting lives of family (6); impulse for drawing up living will?
- cost of care/standards/availability (8)
- elderly distressed at having to sell homes; paying for funeral/wanting money to leave to family
- horror of being put into a home
- should be balance between sacrificial care of family and that provided by state
- many worries would disappear if we were a more caring community
- concern about lack of support for carers (2); love should never be a burden but illness or disability presents strains (6)
- as most can expect to live longer, it will be an increasingly complicated situation for individuals and families
- terminal care usually seen as excellent
- good care is physical, spiritual and emotional
- hope for best care possible; no-one should be denied proper care and compassionate treatment
- people are unprepared – not wanting to think about future
- may be worrying unnecessarily; can do something about it/plan to help alleviate (4)
- should be target to match entry standards (maternity) to exit standards.

4

What are people most afraid of when they die? Being alone? Unbearable pain? Loss of dignity? Being trapped in a body that has become a tomb?

- majority agreement with all the above, plus
- leaving others behind/not saying goodbye/unfinished business – unpreparedness (6)
- dying outside relationship with God; not having a saviour
- loss of mental faculties/ability to communicate (20); the unknown
- reduced quality of life with debilitating illness more frightening than death itself
- being alone might be a benefit – the others are outside our choice and might be good argument for a human agency in death, just as there was in birth
- people seldom show their real feelings – so how do we really know?; depends on individual
- being alone is not a worry; God is with us
- inappropriate attempts to resuscitate people ready to die
- being somewhere I don't want to be – ie. in hospital
- only one cure for fear of death, the Christian message of promise of eternal life in Jesus
- don't think I fear death, in many ways I look forward with some curiosity.

5

What does 'Quality of life' mean?

- will vary at different stages of life/for different people (15)
- might improve after death
- having something positive to experience or give (13); ability to achieve what you set out to do (8); sense of purpose (9)
- ability to maintain dignity/independence (21) mobility/skills; being in control of own decision-making (10)
- ability to communicate and be listened to (17)
- living without severe pain/terminal degenerative illness (12)
 - not burden to family
- enough resources for needs (2); freedom from want or fear (3)
- loving and being loved/valued/respected (11)
- family and friends/relationships (13)
- in some circumstances, knowing the truth enhances quality of life
- living life rather than existing in life (5)
- not being useless (2)
- feeling that life, even if less active, is still worthwhile
- freedom
- God knows
- having faith
- being close to God and people around me, able to be used by him
- no human being has right to define quality of life for others (2)
- support to make the most of your present abilities (6)
- when memories have gone, I don't know what I would feel – just hope I would not be in any pain and would be visited by relatives even if I cannot recognise them, possibly just knowing someone was there.

6

With modern technology it is possible to keep people alive artificially, even when vital organs have failed. How do we feel about that?

- we shouldn't do that (25)
- 'Thou shalt not kill, but needst not strive officiously to keep alive' (4)
- difference between kidney failure at 18 and 90
- waste of money/resources (3)
- grey area; hardest question to answer – depends on age of patient/professional prognosis (7)
- can't be sure if illness will cause death soon or if patient will recover after substantial time – if there is doubt, keep alive (5)
- wrong to keep alive if brain death is proven (4); brain dead is dead
- with medical advances God-given, we should maintain life sensibly (4)
- our own advancement has created more problems than it has solved
- my first feeling is a shudder of revulsion and I want to ask why
- life-saving technology is good – life-prolonging technology, when everything we naturally think of as 'life' has stopped, is playing God and dangerous.

6a

Do we need to make a distinction between assisting someone to die who still has quality of life, and withdrawing medical intervention at the right time?

- majority say yes
- difference between not treating someone and giving drugs to kill them; intention is everything

- is it really living or just not letting go?
- should only be with agreement of patient (7) and family/medical advice; right to choose is paramount
- how do we define quality of life and right time? difficult to decide measurement criteria; assessing when to withdraw medical intervention is key
- quality of life may be considered reasonable by others but unbearable by patient
- who are we to judge?
- do not believe in life at all cost
- assisting someone who has reached the point where they want to die is showing immense love to them
- those who respond to the appeal for help should not be criminalised.

6b

Do we also need to recognise that some palliative treatment makes the patient more comfortable and pain free, but also hastens death?

- majority agree
- yes, but shouldn't be the intention of the treatment (2)
- if there is any quality of life, patient should be helped to live
- most palliative treatment enhances sufferer's life
- comfort and quality of life should take precedence over extending life
- why get hung up on time? – why be afraid to hasten death in this way? (2)
- need for constant review because of scientific advances.

7

What are our fears about assisted dying? Is it that it will be abused by doctors, relatives or nursing homes or hospitals? That there will be untimely deaths of the helpless? Does it send out the wrong signals to society?

- all of the above (42)
- assisted dying is wrong (10)
- devalues sanctity of life (2); ignores God's will; cheapens and degrades life
- who will decide where line is drawn? (2)
- fears well-summarised but greatly exaggerated
- failure of Joffe Bill was a tragedy/URC should support his approach (2)
- why are people so fearful? (2)
- favour assisted dying being made legal
- no fear of assisted dying for self if no quality of life
- pressure on those who are ill (4); if becomes commonplace; those incapacitated could be at mercy of institutions – nothing is totally voluntary; people could ask for assisted dying to avoid perceived burdening of others; exercising own choice may become a battle; who is to be trusted?
- some disagreement on potential for abuse by medical profession/family:
 - Shipman/Allitt were able to act without legitimisation of assisted dying
 - where money is to be made in completion of certificates, some doctors will be less worried about ethics
 - danger in less well-run institutions where bed-blocking is a concern
 - fear, inconvenience and financial considerations will cloud judgement of family
 - with proper safeguards, may lead to reduction in abuse
 - puts too much power in hands of doctors
 - fear of bad and uncaring practice
- 'assisted' needs defining – ensure safeguards/proper and effective controls(32)
- desperate people going abroad suggests something needs to be done; can understand why some people want it; society should accept we are all different

Appendix A – Assisted Dying

- human right to commit suicide – why not help if it's a person's own decision?
- more research needed (2)
- people fear losing control – blame doctors when they have done no wrong
- shouldn't be needed with good palliative care (3)
- once the law has devalued life, who is to stop it being devalued further by anyone with an agenda?
- if dealt with openly there should be no wrong signals and hopefully few fears – if individual has control of own death, that is not abuse
- not morally wrong, but to demand assistance as of right or legally may place too much weight on medical staff
- should trust medical profession/loving and caring families (2)
- people need to discuss dying before they reach stage of terminal illness
- should benefit society overall
- if people of faith emphasised that death is not the end, perhaps some of the anguish around assisted dying could be allayed
- with modern science God has given us potential to 'play God' with life all the time, eg. genetic engineering
- legalising would help a loving partner to carry out the final loving act to a loved one – I would hate to see my partner suffer if s/he no longer wanted to be alive
- the objections to it are far outweighed by the misery caused by refusing to allow it
- we realised, even more clearly, as our Church discussed the issue that our prayers for the medical profession are vital, as they struggle with ethical issues.

8

Suffering is a part of life but when it becomes unbearable do we have a duty to release the sufferer rather than prolong it?

- majority say yes
- no (19)
- 'duty' is the wrong word (18) – 'choice' or 'permission'
- doctors have duty to release patients from suffering by controlling pain properly (12)
- not by killing them; why call it 'release' when you mean kill?
- consider why suffering (pain) is unbearable – poor pain management? lack of skills/resources on part of carers/nurses? lack of commitment?
- is refusing to kill someone to be equated with prolonging their suffering? Compare how we treat animals – but humans are not animals in this sense
- patient must have final say if possible (18)
- modern lifestyle/medicines mean general health is better – so suffering may be prolonged – not always best for patient
- difficult to define where such a point is reached; the most difficult question (16)
- stopping treatment knowing it will lead to death is different from the lethal injection (3)
- unbearable pain/suffering is very subjective (3)
- if suffering becomes intolerable, treatment as administered in hospices should be available
- faith versus humanity – as a human being I feel sufferers should be released but as a Christian I am aware of God in charge in the progress of every situation
- rights and conscience of those who might feel pressured to 'release' someone must be safeguarded
- society, and especially some churches, seem to place too much emphasis on sanctity of life at all costs, rather than quality of life.

9

What do we think about 'Living Wills?' (See Section 7).

- two-thirds of respondents approve: excellent; everyone should be encouraged to produce one while mentally able to do so; with proviso of legal/medical assurance that person is capable of the decision and is acting in own free will; allows dignity in death; sensible and good
- mixed feelings/not happy (9)
- wrong – grieves God and violates his plan (3)
- problem of possible difference between thoughts when preparing living will, and reaching the stage of it being acted on (5); instinct to cling to life is strong
- could help relatives/medical staff reach decision (4); in loving families there should be no doubt of patient's wishes; takes pressure off family and guilt they can feel (7); allows individual to 'speak' even if no longer able to
- huge burden to put on doctors and families
- useful as far as they go (3); not always treated as binding by doctors
- who is to execute the will?
- slippery slope; treading difficult line; could be open to abuse (5)
- should be one factor in complex equation rather than 'legally binding' over eg. views of next of kin
- problems with 'legally binding' – should be proviso for people to change their mind/review (6) without pressure from relatives
- as long as there are safeguards, so that potentially curable or 'improvable' people are not killed
- legislation must be watertight and not have loopholes allowing wide interpretation
- not totally sure why it should be necessary to take this legal step
- most of us are not decisive enough to make one
- have already made/signed one; want to make further enquiries.

10

In all of this, presumably we would want to promote the need for good, readily available, palliative care.

- all those responding agree
- need equivalent of hospices/Macmillan nurses for dementia sufferers and families – would appreciate if C&S committee could look into this
- need for hospices to be able to manage proper home treatment
- example of continuing heart medication for 90 year old with total dementia/incapacitated after severe stroke: family suggested stopping medication and letting death occur naturally: accused of seeking euthanasia
- yes, but not as excuse to avoid grappling with the other issues (3)
- yes, especially if patient can return home/move to proper accommodation for care – hospices can't take all who need to be monitored – hospitals are not the place for the terminally ill; geriatric wards are no place to end a life with dignity
- hospice movement/hospices are beacons of light (8); their role in care and dignity for the terminally ill must be emphasised and extended with NHS finance
- urgent need for practical and emotional support for carers
- should be government funded/part of NHS (5), and not dependent on charity/'luck of the draw'/postcode lottery
- specially trained staff can make a huge difference to patients and those left behind
- especially in hospitals; perception is that hospices do better job than NHS
- if good, readily available palliative care was a common fact then assisted dying would hardly be needed (3)
- this is where society's money and research should be going – if assisted dying became legal, less time and money would be put into promoting and researching palliative care.

Appendix B

Example of a Living Will (Advance directive)

The preparation of a Living Will can offer peace of mind to certain people, and assistance to medical practitioners who may be involved in their treatment. It is becoming more common for individuals to record on a simple form what they wish to happen in their medical care in the future, especially near the end of their life, if they are unable to convey their wishes to their carers, both medical and personal. This may be because they are physically and/or mentally incapacitated, or are unconscious. It concerns their wishes on whether or not they want to be resuscitated or kept alive artificially.

It is possible to write a simple signed statement, or there are various forms available to help. An example of such a form appears below. However, this is not the only form of words which could be used. Every person’s situation is different, and you should consider whether, in your particular circumstances, you need to seek the advice of a solicitor to see whether a more detailed document would be advisable. Remember that a Living Will is different from any ordinary will which you may have made, or make, and which relates to assets you own. The important thing is that others know that you have recorded your wishes, so it is a good idea to discuss it with your next of kin or a near friend, your GP, maybe your solicitor, and give each a copy of the form, and also to have one available in your papers. It is not usually helpful to keep it with your Will! You will probably wish to ask someone to be your “health care proxy”, who would take part in decision-making on your behalf if the living will was needed.

Suggested form for a living will

This is to record my wishes about my medical treatment, to take effect in the event of my being unable to communicate my preferences at a future date. This may be because of physical or mental deterioration in my health, which makes me unable to communicate my views, or because I am permanently unconscious. I understand that I may change my mind at any time, and I will aim to review this document regularly to check that I still agree with it. I understand that I cannot demand any particular treatment, ask for anything against the law (such as euthanasia or assisted suicide); refuse the offer of food and drink by mouth or refuse the use of measures solely designed to maintain my comfort and dignity such as appropriate pain relief, and basic nursing care essential to keep me comfortable such as washing, bathing and mouth care.

I am writing this Living Will as an Advance Directive, and declare that I understand its scope, and am mentally and physically capable of making the decisions contained in it.
I have not been influenced or harassed by anyone else when preparing it.
My wishes are set out below.

FULL NAME
Date of birth
Current address
.....
.....

Nat. Ins. number

Name and address

of GP

.....

Name and address of primary contact(s) – health care proxy(s) *(the person(s) you would like to be contacted to approve the decisions of medical personnel if required by your Living Will):*

Name

Contact address

.....

Telephone number

or

Name

Contact address

.....

Telephone number

My wishes are as follows: I do, however, accept palliative care, including medication, to relieve distressing symptoms such as restlessness or pain, and to retain my dignity as far as possible.

(Delete in each case the alternative 1) or 2) which is not applicable)

A) If I (a) have a severe physical illness and/or a severe mental illness and (b) am unable to participate effectively in decisions about my medical care, and (c) there is very little chance that I will recover in the opinion of two independent medical practitioners,

1) **I do not wish** to be kept alive by artificial means, or to have medical procedures to prolong my life **or**

2) **I do wish** to be kept alive for as long as is reasonably possible using whatever form of medical treatment is available

B) If I become and remain unconscious for months or more, and in the opinion of two independent medical practitioners am not likely to recover,

1) **I do not wish** to be kept alive by artificial means, or to have medical procedures to prolong my life **or**

2) **I do wish** to be kept alive for as long as is reasonably possible using whatever form of medical treatment is available.

Appendix B – Assisted Dying

C) I have specific wishes in certain circumstances named below:

.....
.....
.....
.....

Your signature
(witnessed)

Date

For the witnesses:-

I declare that when the maker signed this document he/she understood what it meant and that, as far as I am aware, no pressure has been put on the maker and that he/she has made it by his/her own wish

Witness 1 *

Signature

Contact details

.....

Witness 2 *

Signature

Contact details

.....

** Witnesses must be 18 or over but not a partner, spouse, relative or anyone else who stands to benefit under the maker's ordinary will*

Review dates and signature:-

Notes

- 1) Living Wills are recognised as being legally enforceable by the British Medical Association, the Royal College of Nursing, the General Medical Council and the Law Society.
- 2) Your Living Will should be discussed if possible with your family, your Medical Practitioner and your 'advocate'. Copies should be deposited with each of them, and you should keep a copy in your papers. You may like to carry a card saying that you have a Living Will, and where it can be found.
- 3) This form applies to England and Wales only. In Scotland a similar procedure is known as 'A Welfare Power of Attorney', which must be granted by the Donor while he or she is mentally competent, and registered by the Donor at the Office of the Public Guardian. The above form could perhaps be adapted.
- 4) A new document is due to be introduced shortly for England and Wales called a Lasting Power of Attorney, but is not yet available.
- 5) The United Reformed Church does not accept liability for the use of this form.

Appendix C

Parish Nursing

The title 'Parish Nurse' is widely used and recognised in North America where nurses operate across denominations and across faiths. In Britain, the term is less familiar. A Parish Nurse might operate within a local church context and provide a number of services that could be summarised as being medically informed pastoral care and health promotion within a spiritual context. Below is an example of a job description for a parish nurse who might operate within Britain.

1. Health Educator

The Parish Nurse will find all sorts of ways of promoting health in the congregation and local community, for example by organising health-care teaching with parent-toddler groups, exercise classes with the elderly, stress management courses with business professionals, or by participating in teaching on drugs, alcohol and sex education with youth groups. Such classes could be in church buildings or beyond. The Parish Nurse will also be concerned about environmental and safety issues and First Aid facilities relating to the church and local community, and will encourage church members to take appropriate actions.

2. Personal Health Counsellor

The Parish Nurse will organise clinic sessions at the church building or elsewhere, when blood pressure checks, weight management, and personal health advice are freely available to everyone in the congregation and community who wishes to attend. In addition s/he will make supportive visits to people who are in particular need because of family illness, bereavement, redundancy or other problems. S/he will also provide health care advice for colleagues in ministry and leadership within the church.

3. Referral Agent

Where necessary the Parish Nurse will make referrals to GPs, dieticians, physiotherapists, counsellors, social service departments and voluntary bodies as appropriate. This will require the development of good local relationships with other health care professionals and wide knowledge of local voluntary organisations.

4. Trainer and Co-ordinator of Volunteers

When a family in the church or community is in need of extra practical care, the Parish Nurse will train and co-ordinate volunteers to help. Unlike many NHS nurses, the Parish Nurse is in communication with many people who want to volunteer but do not know how to get involved appropriately. The Parish Nurse will run First Aid courses in order to equip people to provide practical care in emergencies.

5. Developer of Support Groups

The Parish nurse will identify needs for self-help support and develop groups such as stroke clubs, single parent groups, twins groups, bereavement care groups and so on. The church building may or may not be appropriate for these, but the spiritual and physical elements of health will feature in their programmes.

6. Health Advocate

The Parish Nurse will accompany clients to hospital appointments if desired, and act as advocate for them in all their dealings with health institutions.

7. Integrator of Faith and Health

Prayer and discussion of spiritual issues will form a part of most of the Parish Nurse's interactions with clients so that wholeness of mind, body and spirit are the perceived aims of interventions. The Parish Nurse will be recognised by the church as part of the ministry staff team, even if working in a voluntary capacity.

For more information about parish nursing, go to www.parishnursing.co.uk

Appendix D

Christian Healing Ministry: a brief introduction

There is no one single definition of healing ministry for it encompasses so many aspects of life. It is a biblically based ministry and is seen as the response of the churches to Jesus' commission to preach the gospel and heal the sick. It is about meeting people at their point of need, and helping them on their journey to wholeness.

Healing, wholeness and salvation: These words embrace what God has done for us through the incarnation of Jesus Christ. The New Testament shows us that Jesus' healing of the sick and casting out demons were a vivid demonstration of the coming of the kingdom, and his charge to continue that ministry in his name was part of his commission to his disciples.

- This ministry is in response to Jesus' commission.
- There is the recognition that all healing comes from God and we believe that he works through his body on earth, and so through faith, prayers, and actions we can be part of that process to bring healing and wholeness in body, mind, spirit and the emotions.
- It is the seeking of harmony with God, self, others, environment and creation.
- It is a journey towards living life to the full within our limitations (eg. age, state of health or situation).
- It is truly holistic, concerned with the health and wellbeing of the whole person within a web of relationships, a specific context and history.
- It encompasses and encourages the prayerful and practical support of the whole Christian community for individuals and families and communities experiencing sickness and suffering.
- In practical terms there is a very wide remit, for it embraces most aspects of life where there is brokenness and disease including physical illness, broken relationships, abuse, trauma and depression.
- There is a pastoral aspect, which co-operates with and recognises God working through the medical professions.
- Expression of God's love and compassion for all people and the recognition of his being present in suffering. It is wholly inclusive.
- Through this ministry, human suffering, sickness and healing are put into context, given meaning they could not have apart from the life, death and resurrection of Jesus Christ.
- The ministry of healing is eschatological; it offers healing of the Christian soul within the context of eternity and preparation into eternal life.

Healing ministry embraces forgiveness and reconciliation. Christ's reconciling work on the cross is central to forgiveness and reconciliation. This includes the need to return to the full health of right relationships, starting with the right relationship with God, and recognising our dependency.

Repentance, forgiveness and the dealing with guilt, anger, rebellion and resentment are key to this ministry. So many are angry with God, themselves, or others, and are severely burdened and diseased by the past. Much help is needed to bring some to the point where there can be healing and reconciliation and restoration.

In 2 Cor 5:17-20 we are urged to work towards reconciliation. In Col 1:20 there is a cosmic dimension to Christ's death on the cross; Jesus by his act, reconciled himself to all things whether on earth or in heaven. In Eph 2:16 reconciliation is seen as being supremely concerned with the healing of relationships. Reconciliation is the activity of God and man is the recipient.

The healing ministry works towards peace in the deepest sense of the word – the sense of well being that comes about when the will of God is being done, where there is a harmony of being at one with the purposes of God the creator. It embraces, prosperity, bodily health, contentedness, and good relations between people.

In practical terms for the church, it embraces:

- Pastoral care at all levels.
- Prayer, prayer groups, praying with people, healing services, sacraments, anointing, listening, preparation for death.
- Being involved in the community in whatever way is appropriate for the person and situation, with disabled, ethnic groups, elderly, marginalised, rejected, imprisoned, lonely, vulnerable, sick, terminally ill, bereaved, carers, victims and the frightened.
- Healing of memories.
- Deliverance ministry for people and places.
- Forgiveness and reconciliation.
- Healing services to bring healing and wholeness in the widest sense – not just seeking cures.

Questions asked:

- Are prayers answered? Yes, not always as we want or in our time, but they are answered in God's way and his time.
- Are people physically healed? Yes but not always. We don't know why some are physically healed and others are not. Often healing is not immediate but comes as a package: change of heart, lifestyle, seeking of forgiveness, medical intervention and prayer.
- Do miracles still happen? Yes, peoples' lives change against all the odds.
- What is the usual response to healing? To go and tell others and serve the Lord, and live life to the full. There is a new joy and excitement as people experience the living God and become powerful witnesses.

Useful books on the Healing Ministry

A Time to Heal (a manual), Church House Publishing 2000. ISBN 07151383
Francis MacNutt, *Healing*, Hodder and Stoughton 1997. ISBN 0340661402
Francis MacNutt, *The Prayer that Heals*, Ave Maria Press. 2005. ISBN 1594710554
Agnes Sanford, *Healing Gifts of the Spirit*, Arthur James 1979. ISBN 0853052107
Randolf Vickers, *The Anointing to Heal*, Terra Nova Publications 2005. ISBN 1901949389
John Gunstone, *A Touching Place*, Canterbury Press 2005. ISBN 1853116319
Healed, Restored, Forgiven. Prayers and Liturgies, Canterbury Press 2004. ISBN 1853115878
R T Kendall, *Total Forgiveness*, Hodder and Stoughton 2001. ISBN 034075639X
Nicky Gumbel, *Why does God allow suffering*, Kingsway 1999. ISBN 0854768629
Ian Cowie, *Jesus healing works and ours*, Wild Goose Publications (Iona Community) 2000. ISBN 1901557278
Ruth Burgess and Kathy Galloway (eds.), *Praying for the Dawn*, Wild Goose Publications (Iona Community) 2000. ISBN 190155726X

Study Guide

This Study Guide has been produced for use with the report on Assisted Dying. The subject is complex and there are no easy answers to the problems associated with end of life issues, suffering and death. The Guide is designed for small group discussion, and is in seven parts which can be used over a series of sessions. Each section looks at particular issues to do with assisted dying, and includes reflections, biblical references and questions for group conversations, and relates directly to a section in the report on Assisted Dying.

Contents

1. Introduction
2. A Reformed view
3. Suffering, dying and fears associated with end of life issues
4. Practical considerations
5. The elderly
6. Living wills – advance directives
7. Where do we go from here?

Suggestions for use

Each module can be used as a basis for discussion for one session or more, depending upon interest and circumstances. It is suggested that each session commences with prayer and a Bible reading. There is a prayer at the beginning of each section which you may find helpful. Some of the issues are very delicate and may become personal and distressing. Be sensitive to one another and respect differing views, experiences and feelings. Pastoral follow-up may be needed after discussing some of the issues.

Make a note of your thoughts, ideas and concerns as you go along, the issues to pray about, and what, if any, changes you would like to see within the church, community, society, family, amongst friends and from yourself. May it be an enriching experience.

1. INTRODUCTION

Prayer

Gracious God, thank you for giving us this opportunity to spend time together to discuss the complex issues about life and death and the mystery of suffering. Give us grace to listen to one another with open minds and be understanding when others have differing views from ourselves.

May we discern your words of wisdom, your truths as your Holy Spirit moves amongst us. May we be aware of your loving presence as we seek your guidance through the scriptures, prayers, and listening to one another.

In Jesus' name, Amen.

Where O death is your victory? Where O death is your sting? 1 Corinthians 15:55

See Sections 1-3 of the report and case studies.

If someone you loved was suffering unbearably, had lost their quality of life, and dignity, and wanted to die...what would you want for them?

Would you be assured that they would be called home in God's good time?

Or would you want to help them towards a gentle release? The answer isn't easy.

For Christians, ethical and moral dilemmas rarely are.

Some seek clear theological guidance; others are influenced by traumatic personal experience.

Assisted Dying – the notion that people of sound mind, who are terminally ill and suffering unbearably might receive medical help to end their lives – has become an issue of hot debate. Although an attempt to legalise this was defeated in the House of Lords in 2006, it is sure to re-emerge (2.1).

As Christians, we see death as an ultimate healing. Many feel there is a time to die, and that it might not be right to use medical advances to keep people alive artificially, when all quality of life is gone. But there are real concerns about positive action being taken to end life. During the House of Lords debate, the Archbishop of Canterbury said:

"Whether or not you believe that God enters into consideration, it remains true that to specify ...conditions under which it would be both reasonable and legal to end your life, is to say that certain kinds of human life are not worth living (2.2)."

Dignity in Dying (formerly the Voluntary Euthanasia Society) takes the view that health care professionals frequently break the law, out of compassion and respect for the wishes of terminally ill patients, and the choice is:

"...not between permitting and preventing medically assisted dying. The choice is between making medically assisted dying visible and regulated, or allowing it to continue 'underground' without any safeguards, transparency or accountability (3.7)."

Questions

1. **Have you had personal experience of a loved one suffering, and of wondering whether it would be better if death intervened? Did faith help in your situation?**
2. **Do you believe that human life was given by God, and should therefore only be taken by God, in God's good time?**
3. **Do you see circumstances in which the power to assist in a person's death might be misused – by medical staff or by family?**
4. **What about the view of Dignity in Dying that it happens anyway, and it would be better if it were regulated?**
5. **Do you see a distinction between assisting a person to die and keeping someone alive artificially? Do you agree with Arthur Hugh Clough? He said *Thou shalt not kill, but needst not strive, officiously to keep alive* (5).**

Different views are more fully explained on various websites: (See 12. Sources of Further Information).

2. A REFORMED VIEW

Prayer

Gracious God, we thank you for creating the world in all its richness and beauty, and that we are a part of your creation, and have been given the gift of life. You have given us communities, families and friends in which to live and grow, may we seek to understand more of your truths so that we may use our time and our lives wisely, to your glory. Help us to value life, and know that when the time comes, death is not the end, but a new beginning still surrounded by your love. Give us the grace and wisdom to be open to discern your truth and will for your people, and in the midst of suffering know your love. In the name of Jesus Amen.

See Section 4 of the report.

The section of the Church and Society report entitled 'A Reformed View' is an attempt to identify some of the central theological and ethical issues at stake in the assisted dying debate and to ask how a Christian Church in the Reformed tradition should respond to those issues. This section of the study guide offers some more general comments about how the Reformed tradition might shape our moral living, thinking and decision-making. This might help explain some of the thinking behind the more specific arguments in the report.

The United Reformed Church 'acknowledges the Word of God in the Old and New Testaments, discerned under the guidance of the Holy Spirit, as the supreme authority for the faith and conduct of all God's people' ⁽¹⁾. This formula identifies a central role for our Scriptures in shaping our doctrine and ethics. It also, deliberately, admits of a wide range of interpretations of Scripture and understandings of the nature of its authority. It allows a role for other sources (usually summarised as tradition, reason and experience) in theological and ethical thinking, and allows for a certain amount of prayerful improvisation on the part of a believer, or believing community, faced with new situations and questions.

When 'discerning the Word of God in Scripture', we need to remember that the biblical writings come from very different historical and social contexts from ours, and might not directly address our questions and concerns. We will not find within the Bible any formula for addressing the hard questions of contemporary medical ethics. In addressing these questions, the Bible functions most importantly in what New Testament scholar Richard Hays calls a 'symbolic world' mode ⁽²⁾. That is to say, it informs the Christian community's vision of the world, its relation to God, and our place within it, re-shaping the community's moral imagination along the lines of that biblical world-view. This re-shaping of the moral imagination happens (or should happen) centrally in the worship and shared life of the Christian community.

As Christians participate in the Church's worship and corporate life, this should enable them to grow in Christian character and to develop virtues, including a kind of 'practical wisdom' informed by faith, that will help them to live and act well in the morally testing situations which they encounter. This approach suggests that faithful Christian living will indeed involve an element of moral improvisation in response to new situations, but this does not mean that everything is up for negotiation. Some hold the view that Christian ethics does include moral principles and rules that are absolute and exceptionless, or as near as makes no difference.

It is possible to outline some features of a biblically-shaped 'symbolic world' that are particularly relevant to the issue of assisted dying:

(1) United Reformed Church Basis of Union, para. 12.

(2) Hays, *The Moral Vision of the New Testament*, Edinburgh: T & T Clark, 1997

Human life, in common with the whole material world, is created by God, who loves it and has pronounced it 'very good'. However, human life and the world are flawed and alienated from God in profound and complex ways (in traditional Christian language, 'fallen'). But God has responded decisively to this predicament, offering humanity and the world, the hope of healing, reconciliation and ultimate fulfilment in and through the life, death and resurrection of Jesus Christ.

Because humans are God's creatures, our life is not our own, but is given to us as a loan or gift by God; this understanding lies, for example, behind the biblical prohibition of murder.

Because every human is one of God's beloved creatures, for whom Christ died, every human life has great and unconditional value. No human life, however limited, damaged or dependent, is beyond the reach of God's love. This should make us highly suspicious of the claim, often made in discussions of medical ethics, that some human lives are not worth living, or that some human individuals have less of a claim to our respect and protection than others.

However, it would be misleading to talk of human life in this world as having an 'absolute' or 'infinite' value: Christians have not usually thought that human lives should always be prolonged at all costs. Indeed, the Christian tradition of honouring martyrs suggests that there are situations in which it is wrong to cling to life. The Christian faith in the resurrection of Jesus Christ means that our hope is not 'for this life only' (1 Cor 15:19), and that God's loving care for us does not cease with our death.

A major theme in the Bible is God's covenant relationships with humankind, and with particular communities (notably Israel and the Church); this leads some Christian ethicists to think of particular human relationships, including marriage, family life and professional/patient relationships in health care, as covenant relationships that call for particular virtues and impose particular obligations.

Questions

- 1. What does it mean to be created by God and how does that relate to our attitudes towards life and death?**
- 2. What do we understand by a covenant relationship with God? How do we honour that relationship with God?**
- 3. How do we value human life? Does the value of a human life ever become worthless?**

3. SUFFERING, DYING AND FEARS ASSOCIATED WITH END OF LIFE ISSUES

Prayer

We give thanks Lord, that we have come together to think and talk about the great mysteries of suffering and death. We thank you that you have an everlasting love for us, and that you want us to love and care for others.

We are often afraid to talk about suffering and dying because we do not know the answers to these mysteries and we are fearful in case we upset others and unsettle ourselves. May your Holy Spirit guide us as we look at the scriptures and speak with one another. Help us to understand more of your love for us and for all people and give us insights into the mysteries of suffering and death and take away our fear. Help us in our discussions to be sensitive to one another's feelings and help us to know how we should act as individuals and as a church or group in respect of end of life issues.

Thank you that you died and suffered and rose again for us, so that we may know more about the mystery of death and life everlasting. In Jesus' name, Amen.

Bible Reading

Luke 10: 25-37. Mark 12: 28-34. Matthew 19: 16-19. James 5: 13-16

See Sections 4.3 – 5 of the report, and most other sections. Also see case studies and Appendix D (healing ministry).

This is not a subject that can be addressed in isolation for we live in communities, thus it relates to the whole of the report and the Appendices. However we will endeavour to focus on just a few aspects in this section to try to unravel our understanding of suffering and our response to it.

Our responses to these issues will be informed by our faith, the teaching we have received and our own experiences. By listening to one another you may come to a different understanding and to see things from a different perspective.

First, let us look at suffering from the theological perspective highlighted in section 4.3 of the report which addresses suffering; you may find it helpful to re-read that section (or read it aloud if you are in a group).

Questions

- 1. What does loving your neighbour mean?**
- 2. What is suffering? Is it only physical or are there other forms of suffering? Can we see suffering in isolation?**
- 3. Are we afraid of suffering for ourselves or others? If so, how does that affect our response to suffering?**

'Thou shalt not kill' is one of the ten commandments. Our dilemma is how to respond to extreme suffering and pain, especially when the patient requests help and when complete relief is not possible, to help or allow the patient to die. Here we enter the realm of palliative care and hospices (see module 4 of this Study Guide), Living Wills (module 6) and social and political matters (module 1).

Share with one another any experiences of suffering you feel relevant.
In your opinion was this dealt with in the best possible way?
If not, how could it have been dealt with differently?
Were you involved in any decision making?

From the pastoral and practical perspective look again at section 5.7 of the report (if you are in a group, you could read it out loud).

This gives the church many things to discuss in respect of how we respond to caring for sufferers in practical ways. The Lord taught us and showed us how to pray, in James 5: 13-16 we are urged to pray when anyone is in trouble, it is something we are all called to do as Christians.

Much will depend on individual circumstances. You may like to discuss:

1. Do we pray enough? If not, how could we encourage one another to pray for others?
2. If all resources were available, money, time, people, expertise, etc., how would we aim to alleviate suffering?
3. With the resources we have, what should be our priorities in our community, or nationally?
4. What do you think of the idea of parish nursing? Is it relevant for your area? (See Appendix C).
5. The Healing Ministry encompasses all aspects of life. Can you see areas where it operates in your church already and might it be developed further? (See Appendix D).

If you would like further information contact your Synod Adviser for the Healing Ministry or see the recommended book list at the end of Appendix D).

You might like to make notes of your responses to these questions.

Take time to pray about all you have discussed and be pastorally sensitive to those in the group who have not found this subject easy.

4. PRACTICAL CONSIDERATIONS

Prayer

Loving God, we thank you that you have gathered us here to think about and discuss the issues of illness and suffering at the end of life. We ask that your Holy Spirit may guide our words and thoughts so that we are in tune with your will. Show us how best to care for those near death, enabling them to know they are loved and valued in surroundings in which they are comfortable and pain free. Help us to be mindful too, of the lonely, frightened and hurting people who have no one to love them or bring relief. In our modern society, show us how we determine the right time to die when someone is suffering, and how best we can care for them. Help us all to value life and live each day to the full within our limitations of age and health. May we remember that death is not the end but a new beginning with you, surrounded by your love In Jesus' name, Amen.

See Section 5 of the report, case studies, Appendix C (parish nursing) and D (healing ministry).

Bible Reading

John 14: 27 (14-27) John 13: 12-17 (1-17) Romans 12: 1-19

Re-read paragraph 5.1 of the report. If you are in a group, it might help to read this aloud.

This gives us profound dilemmas as Christians as we seek to follow Christian teaching and view the situation in perspective and give meaningful and helpful support and comfort. Our natural instinct is to offer pastoral care, but sometimes even that feels beyond us in the most extreme of situations, and we flounder.

What can we do in these sad and prolonged situations of terminal decline? Our pastoral response will depend on whether the patient is at home, in hospital or in a hospice or nursing home, whether there is a large supportive family or just one carer, or no family. Also the wishes of the patient and family must be respected when they prefer not to have visitors.

As Christians we recognise we are made up of body, mind and spirit, and we function in relationships. There are many types of suffering, not just physical, and when addressing end of life issues we must heed the necessity to address not just physical, but also spiritual, mental and emotional needs. This brings us to peace of mind which is important at all stages of life, and especially at the time of death. (Refer to 5.3).

Visiting the terminally ill is not always easy, and many shy away from it, though training can be helpful. The length of the visit and the timing has to be carefully gauged, and sometimes 'just being there', is enough.

Appropriate conversation can be valued, but most of all the person still needs to be treated as a person, not an illness, to have their needs and dignity respected. The pastoral visitor must be sufficiently aware to listen and meet them at their point of need.

Appropriate prayers, visits, practical help and the opportunity for the patient to talk to someone confidentially about the big issues, personal confessions, the meaning of life and death, etc. to have someone to pray with them and bring Holy Communion may help to bring peace of mind.

Palliative care is managing and relieving extreme pain and discomfort through medication and appropriate care. Hospitals can offer excellent end of life palliative care but are often too busy to devote the time to long-term terminally ill patients.

The hospice movement offers specialist palliative care for the terminally ill at home, in a hospice, special hospital unit or care home. This is usually excellent, with the patient receiving expert pain relief, care with the emotional and practical needs of family and friends being met as well. Hospices are usually quieter than hospitals with staff having time and training to deal with end of life issues. Through the trained chaplains, appropriate spiritual care is offered; this can bring peace of mind to both patient and family and friends.

Chaplains in all these situations have an important role in bringing spiritual help and comfort to the suffering and dying. However, there is insufficient capacity to cope with all who are terminally ill (see paragraph 5.5 and section 8 of the Report). Inevitably some die in hospital alone, in geriatric wards where staff are busy.

For those looking after dementia sufferers, there is an even greater problem, how and where best to care for them, especially when other terminal illnesses add to the problem? (These issues are explored further in module 5 of this Study Guide.)

There are no easy or universal answers. Each group discussing these issues will have their own experiences to draw on. You might find it helpful to look at the responses to the questionnaire (Appendix A) at this stage, as many are relevant to the practical considerations raised.

Questions

- 1. What are Christian responsibilities when it comes to caring for the terminally ill? Do we tailor our responses to the situation i.e. when the patient has a large supportive family and friends or when there is no family at all? Look at the case studies and draw on your own experiences.**
- 2. Take a look at Appendix C on Parish Nursing. Could this be helpful when addressing end of life issues?**
- 3. In your experience, is hospice care widely available or are there limitations in the availability of places?**
- 4. Take a look at Appendix D on the Healing Ministry. Could you see this as an extension of pastoral care relevant to the situations we have been discussing?**
- 5. If there is a serious problem with care for someone who is terminally ill, what should we do, if anything? If there is no space in the hospice, what then? What are the issues to be considered before intervening?**
- 6. Hospices are often under-resourced. How can the church offer support?**
- 7. Do you liaise with, value and support your hospital chaplains in their special role?**
- 8. How can the church and individuals best support the patient, family, carers, chaplains and friends?**

5. THE ELDERLY

Prayer

O Lord God, look with mercy on all those whose increasing years bring them isolation, distress, or weakness. Provide for them homes of dignity and peace; give them understanding helpers, and the willingness to accept help. And, as their strength diminishes, increase their faith and their assurance of your love.

We pray in the name of Jesus Christ our Lord. Amen

See Section 6 of the report.

For many old people there is much time available, perhaps too much, to sit and ponder over their lives, with success and failure, opportunities taken and missed, relationships broken and not restored.

Malcolm Johnson highlights the 'anguish' which many old people endure in paragraph 6.4 of the report. He speaks of 'biographical pain', which includes promises made but unfulfilled, wrongs unable to be righted, leading to guilt and self-loathing:

"Some see this as unforgivable sin, others, with no belief, simply feel tortured. Yet they rarely find a sympathetic and safe listener to relieve this profound distress..."

The following meditation, 'Old Nun's Prayer' could provide the basis for a full discussion on the agonies of those who are growing old and dependent. It may be helpful to read it straight through, and then invite people in the group, or ourselves if alone, to recall situations with elderly relatives or friends who may have these thoughts – or indeed ourselves, whatever our age! It is in many ways a positive conversation with God, sorting out what is a good way to deal with old age!

Lord, thou knowest better than I know myself that I am growing older, and will some day be old. Keep me from getting talkative, and particularly from the fatal habit of thinking that I must say something on every subject and on every occasion. Release me from craving to straighten out everybody's affairs. Keep my mind from the recital of endless details – give me wings to come to the point.

I ask for grace enough to listen to the tales of others' pains. Help me to endure them with patience. But seal my lips on my own aches and pains – they are increasing, and my love of rehearsing them is becoming sweeter as the years go by. Teach me the glorious lesson that occasionally it is possible that I may be mistaken. Keep me reasonably sweet. I do not want to be a saint – some of them are so hard to live with – but a sour old woman is one of the crowning works of the devil. Make me thoughtful – but not moody; helpful, but not bossy. With my vast store of wisdom it seems a pity not to use it all. But thou knowest Lord, that I want a few friends at the end.

Responses to the questionnaire raise further issues. Question 3 focused on the elderly: "Are we worried about becoming a burden, restricting the lives of carers, using up family resources and not getting good care?" (See Appendix A, 3.)

Questions

1. How can we as Christians ensure that people who are old and frail do not feel themselves to be a burden? What work is undertaken by us as individuals and churches to help old people to feel a) valued? b) secure?
2. How can our dignity be maintained if we become disabled, frail in mind, dependent? As God's people are all equal in his sight, created by him and, as Jesus taught, loved by him, do we have a special responsibility to care for the elderly?
3. What about Christian Homes and Nursing Homes – are there any in your area, and how are the churches involved? What worship services are held in Homes, Hospitals, and are special prayers and themes chosen?
4. How could we achieve the same standard of care for the elderly dying as is available in the Hospice Movement? There is no way at the present time that all those who need hospice care can have it . 'It should be a target to match exit standards with entry (maternity standards' (Appendix A, 3.)

6. LIVING WILLS – ADVANCE DIRECTIVES

Prayer

We thank you that we are a part of your creation. There is much we do not understand about life, death and suffering and thus we are sometimes fearful and unsure how to best deal with the end of life issues, especially when there is suffering in body, mind or spirit or all three. Some may have experienced suffering in others or caring for a loved one and one is aware of the strain and anxieties cast upon the carers. In our discussions, may your Holy Spirit direct and guide us and bring us comfort as to the way forward for ourselves and others. As we discuss Living Wills, may we be honest with ourselves and each other, about our fears of losing control of our lives and having suffering over which we have little or no control. We want to value life with all its richness and possibilities, but also want to recognise the right time to let go and not prolong suffering. We thank you that you gave your life for us and overcame death, and showed us that death is not the end, but after death we have everlasting life with you still surrounded by your love. In Jesus' name, Amen.

See Section 7 of the report and the example of a Living Will (Appendix B).

The preparation of a Living Will can offer peace of mind to certain people, and assistance to medical practitioners who may be involved in their treatment. Take a look at the example of a Living Will in Appendix B.

It is becoming more common for individuals to record on a simple form what they wish to happen in their medical care in the future, especially near the end of life, if they are unable to convey their wishes to their carers, both medical and personal. This may be because they are physically and /or mentally incapacitated, or are unconscious. It concerns their wishes on whether or not they want to be resuscitated or kept alive artificially.

Study Guide – Assisted Dying

It is possible to write a simple signed statement, or there are various forms available to help. Appendix B is an example of such a form, or you may like to ask a solicitor to provide a more detailed document. The important thing is that others know that you have recorded your wishes, so it is a good idea to discuss it with your next of kin or a near friend, your GP, perhaps your solicitor, and give each a copy of the form, and also to have one available in your papers. It is not usually helpful to keep it with your Will! You will probably wish to ask someone to be your “health care proxy”, who would take part in decision-making on your behalf if the Living Will was needed.

It is at times when people have experienced the dying of loved ones or friends that the subject comes into focus, especially if the experience is not a good one.

When “DNR” (Do Not Resuscitate) is written on hospital notes without the knowledge of – or discussion with – the patient or relatives, distress is caused.

Confusion by some carers about what is euthanasia may cause unnecessary interference. If there is a Living Will that may help to avert this, but there is no guarantee that the patient’s wishes will be known or accepted.

Health workers on the whole welcome Living Will instructions as a factor in their choice of treatment, given the provisos of appropriateness at the time of decisions. Though these may have legal standing there is still uncertainty about how they should be interpreted. As litigation increases, especially in hospital, a written statement of the patient’s wishes can be very helpful to doctors and nurses in making correct choices of treatment, with the written Living Will to guide them.

Questions

- 1. What is a suitable time to bring up the subject of living wills with family and friends? Do you know anyone who has made one? Do you have experience, first- or second-hand, of caring for someone so incapacitated that you were consulted on decisions that must be made for them on artificial prolongation of life? Were these decisions difficult to make? Was there a Living Will available and if so, was it helpful?**
- 2. Are there dangers in persuading someone to fill in a form expressing their wishes? Might there be pressure on them to make a choice for the sake of others, which they did not really want? How can we explain that this is not euthanasia, (it is not helping the person to die), but accepting that it only applies if they would die if left without artificial aid, either medical or mechanical?**
- 3. What has our Christian faith to say about our making life-or-death decisions for: a) ourselves? b) others? Is modern medicine always helpful as it enables people to be kept alive artificially, indefinitely? There are continuing advances in transplant surgery – heart, lung, liver, kidney, face. Is there a limit to ethical use of transplants to prolong our natural lifespan? Are we in danger of interfering with God’s created order?**
- 4. If we believe in life after death why do we cling on to this mortal life in spite of sickness and suffering?**
- 5. Does the fact of Jesus’ miraculous healing affect our choice of artificially prolonging our life, in case we might undergo a miracle cure in the future? (Jairus’ daughter healed – St Mark’s Gospel chapter 5, the story of the raising of Lazarus – St John’s Gospel, chapter 11.)**

After this session, be pastorally sensitive and supportive to one another, especially if someone is caring for a loved one who is terminally ill, or who has had a recent diagnosis.

7. WHERE DO WE GO FROM HERE?

Prayer

Gracious God, we give thanks for the richness of the discussions we have had. Thank you for opening our eyes to the many issues it has raised, and that as a group we have had the opportunity to share experiences, concerns and to think about issues in a new way. We ask that you will help us as we discuss ways forward, help us to focus on the real needs in our church, community, family and amongst our friends. May your Holy Spirit move amongst us as we seek to discern the way forward, as individuals, and as a group or church. May we seek to help others to have peace of mind and feel safe and loved as they face the end of life. Show us how to be your body here on earth. In Jesus' name, Amen

Reflect on your discussions and refer back to your notes. Are there any areas for prayer or change?

as a church
as a denomination
as a group of people
as an individual
as a family
ecumenically

Does anything need changing? Attitudes, procedures, level of care?

as a church
as a denomination
as a group of people
as an individual
as a family
ecumenically

What can I/we do? Are there any ideas for the next step?

as a church
as a denomination
as a group of people
as an individual
as a family
ecumenically

We live in a secular culture where many are afraid to talk of death. It is often remarked that, while the Victorians were shy of talking about sex but always ready to speak of death, we have the opposite tendency. But within our Christian faith there is plenty of space for talk of death. For some who are dying or facing the death of someone they love, the Church is a place where this cultural taboo is lifted and where, with relief, death can be spoken of. We say much about the death of Jesus and about what we believe his death means for us within God's love – the salvation of the world, the forgiveness of sins, and the defeat of death itself. We also speak about the

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meaning of our own death and of the promise of eternal life, sometimes in terms of immortality, but predominantly in terms of resurrection. As Christian people, we also say a good deal about the meaning of life, about its sanctity and dignity, of how life itself is a gift from God and of how human beings are made in the image of God. We have begun to talk again about what it means to have a 'soul' (perhaps in response to a secular culture which mourns the loss of its 'soul'). Christian theology is rich in the language of life and death of its meaning.

At the same time Christian people, along with others, have been wrestling with the 'end of life' issues discussed in this report. We have often found it strikingly hard to make the connections between our theological talk, the language and hope of our faith, and the moral and practical questions of assisted dying and euthanasia. Sometimes people use theological arguments to defend an ethical position, but it is not always clear that the one necessarily leads to the other. Many argue that a belief in the sanctity of life means that it would be wrong to assist anyone to die. But before we reach that conclusion we must ask what it means to say that life is holy. It may indeed mean that life is God's gift to us, but does that mean that we may play no part in taking decisions over its end? (Christians are still divided, for example, over whether a recognition that life is God's gift permits or forbids the use of contraception).

It could be argued that God has given us our lives, but also invites us to make mature decisions about them, in ways which are also in response to a holy responsibility. If we are stewards of creation, are we not stewards of our own lives? Also, we have to think carefully about what it means to affirm that death is defeated. In many Christian traditions death is the ultimate enemy, while for others it may also be considered a friend – or simply the marking point of a transition from one life to another. What would this mean for making decisions at the end of life? It may not be at all or obviously clear! Again, you might think it straightforward to conclude that Christians should never choose death for themselves, but trust God to choose the time. But this is not quite how Christian martyrs have seen the issue. When Christian discipleship is often seen as a growing into maturity, the maturity of Christ even, then what do we say about serious choices over life and death? Some might say that to assist anyone in dying is to 'play God'. But what then do we make of the biblical insight that we are made 'in the image of God'? It is often assumed that theological reflection on these issues leads only in one – obvious – direction, but that is an oversimplification.

Within this paper a range of views about this subject are presented. Malcolm Johnson's views are rooted in theology as much as Neil Messer's, for example. But they come to different conclusions. Is it that one is wrong and the other right, or that both reveal what the other neglects, so that we can see, as we hold them together, a more nuanced view? It is our hope and prayer that the report, and the study guide, has helped inform and equip you on your own Christian journey and in choices you may be called to make.

