

From Professor David Short, M.D., FRCP, FRCPE

A PHYSICIAN'S MISGIVINGS REGARDING THE ADVANCE DIRECTIVE

Professor Short's caveat introduces three recent pamphlets on living wills and euthanasia—two from the UK, one from the US. They complement each other well, illustrate the international character of the debate, and mark the fateful decision of the Dutch Parliament, just reported, to formalize the first euthanasia jurisdiction in the modern world.

I wish to make it clear at the outset that I am an advocate of patient autonomy. I feel strongly that patients should make their own decisions regarding treatment; considering medical advice but not feeling bound to follow it. I am opposed to any form of strong paternalism.

Having said that, I have great misgivings over the current enthusiasm for the Advance Directive for the following reasons:

1. The individual who draws up the advance directive has no basis for making an informed decision, because the precise situation which he or she will face cannot be foreseen. They do not know what age they will be, whether they will have dependents and, most important of all, what the prospects of recovery will be. That is why a considerable proportion of patients do not necessarily want their advance directives followed strictly (see *JAMA* 1992, 267, 59).

The strong support given to the Advance Directive by the Voluntary Euthanasia Society shows clearly that it is designed to lead to the legalisation of euthanasia. Such an outcome would, in my view, be the greatest imaginable disaster both for patients and doctors.

2. An individual cannot foresee what changes may take place in his or her attitude over the years. There are many examples of people who have changed their minds when illness has struck. The healthy do not choose in the same

way as the sick (see *BMJ* 1985, 291, 1620). (That is why most polls on euthanasia are useless.)

3. The strong support given to the Advance Directive by the Voluntary Euthanasia Society shows clearly that it is designed to lead to the legalisation of euthanasia. Such an outcome would, in my view, be the greatest imaginable disaster both for patients and doctors.

Starvation leads slowly to inevitable death; so there would undoubtedly be 'compassionate' demands that the patient should not be allowed to linger but should be given a lethal injection. In other words, it would be a step into the realm of euthanasia.

4. My final objection to the Advance Directive is that it puts the onus on the public to demand a quality of medical care which they are entitled to expect as of right. Patients are entitled to expect treatment which is compassionate and intelligent; the quality of treatment which a doctor would wish to receive himself. In my view, it is doctors not patients who ought to be encouraged to sign a declaration: a declaration to the effect that they will never knowingly administer futile treatment or prolong suffering without a real hope of recovery.

With regard to instructions in an Advance Directive sanctioning the withholding of food and water, my attitude is that this is unacceptable. Starvation leads slowly to inevitable death; so there would undoubtedly be 'compassionate' demands that the patient should not be allowed to linger but should be given a lethal injection. In other words, it would be a step into the realm of euthanasia.

Speech given to a meeting in the Palace of Westminster in London, 24 July 1992.

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A TIME TO LIVE, A TIME TO DIE: ADVANCE DIRECTIVES AND LIVING WILLS

WHAT IS A LIVING WILL?

A 'living will' is a type of health care document known as an 'Advance Medical Directive.' An advance directive is a generic term for a form or document which expresses your preferences regarding medical treatments to be implemented in the event you are physically and mentally unable to make medical care decisions for yourself. That is, an Advance Medical Directive is a method of letting others know your wishes about treatment if you are unable to communicate those wishes at the time. There are several varieties of medical directives, including living wills, durable powers of attorney for health care, values inventories, etc.

A 'living will' is a specific kind of directive which is 'restricted to rejecting life-sustaining medical interventions, usually, although not exclusively, when a person is terminally ill'.¹ Living wills have been in existence for over 20 years. Nursing homes and senior citizens' centers have been supervising living will signings for several years. Developing medical technologies, publicity about euthanasia and doctor-assisted suicide, and recent legislation have focused greater attention on living wills.

On December 1, 1991, the Patient Self-Determination Act became federal law. This law requires personnel at all hospitals, nursing homes and hospices receiving Medicare and Medicaid reimbursement to advise patients upon admission of their right to accept or refuse medical treatments and to execute an Advance Medical Directive. These medical personnel must (1) document whether patients have directives, (2) implement medical directive policies and (3) educate their staffs and communities about medical directives.²

Between 4% and 17.5% of adults have completed an advance directive. In a 1988 public opinion survey conducted by the American Medical Association, 56% of adults reported that they had discussed their treatment preferences with family members. Only 15%, however, had completed a living will. . . . In one study of nursing home residents, 90% had heard of a living will, but only 18% had signed one; 30% had heard of a durable power of attorney, but only 15% had appointed a decision maker.³

While a living will may sound harmless and even desirable, there is the very real potential for future abuses. Before filling out a living will, be certain that you fully understand how much power and responsibility you are giving an attending physician.

WHY MIGHT I WANT A LIVING WILL?

A living will is, in fact, a 'dying declaration,' stating the circumstances under which a person wishes to be permitted to die without certain medical treatments.⁴ There are several common reasons individuals give for desiring a living will. Most persons find it reassuring to know they will have some control of their treatment, through a living will, even when they become incompetent. Some persons fear too much medical treatment will be forced upon them when they are near death. They don't want to have their dying prolonged by machines and fear leaving their families with exorbitant medical bills. Some individuals find that specific planning eases their anxiety about death. Finally, some want to spare their loved ones from these difficult decisions.

WHAT BIBLICAL PRINCIPLES APPLY TO LIVING WILLS?

No matter what the issue or technology, the Christian must always ask the question, 'What does the Lord say? Are there precepts, principles or examples in the Bible that help us understand our Heavenly Father's will on the matter?' While it is true that living wills are not mentioned in the Bible, it is not therefore true that the Bible has nothing to say about them. The Bible has much to say about life and death.

First, the Scripture says that human beings are made in the image of God, and he has invested our lives with sacred value (Gen. 1:26-27). Scholars disagree over the precise ingredients that make up the image of God in humanity, but at least one thing is clear: human beings have a value and a unique place above all other forms of life on the earth. 'To sanctify' means to 'set apart' as special. Since God has set human life apart above all

other life, we refer to the sanctity of life. The psalmist declares that we are 'made a little lower than the angels' and are 'crowned . . . with glory and honor' (Ps. 8:5). The sanctity or sacredness of human life is a biblical doctrine that must be considered in any application of the Bible to medicine or science.

Second, the Bible teaches that God himself is the giver and taker of human life. He is sovereign over human life. As Paul puts it in Romans 14:7-8: 'For none of us liveth to himself, and no man dieth to himself. For whether we live, we live unto the Lord; and whether we die, we die unto the Lord: whether we live therefore, or die, we are the Lord's'. The Lord himself is the giver of life and the one who takes life (Job 1:21). Whatever we decide about end-of-life issues, we must understand that we do not possess ultimate authority over life and death.

Third, the Bible everywhere condemns unjust killing. In fact, God clearly declares capital punishment for anyone, who with premeditation, unjustly kills another person (Gen. 9:6).⁵ There is no warrant in Scripture for active euthanasia or the intentional killing of another person because his or her condition appears terminal.

Fourth, Christians have the assurance of eternal life and the promise of the resurrection and must not be enslaved by the fear of death (Heb. 2:14-15). We have been set free from the fear of death through Christ, who conquered death for us. One of the most threatening things about death is that we have so little personal experience of it. But we do have the testimony of Scripture. Paul says, 'to be absent from the body is to be present with the Lord' (2 Cor. 5:8), and Jesus tells us that, for the Christian, the life to come is blessed, glorious and will consummate with a resurrection body (John 14:1-4. See also Paul's powerful description of the resurrection in 1 Cor. 15:12-58).

Doctors, other care givers and family members want to know the wishes of their patient and loved one when the time of death is near.

Fifth, while suicide is not 'the unpardonable sin', the Bible nowhere condones or speaks approvingly of suicide (1 Chr. 10:4, 13; Matt. 27:3-5; 2 Sam. 17:23; 1 Kings 16:18-19). Whatever you decide about end-of-life issues, suicide or active self-killing is not a biblical option.

As we continue to consider medical directives, it is crucial that we keep these biblical principles in mind. They will be our guide in making decisions about the end of life.

As we have already seen, there are several reasons people support the use of living wills. Doctors, other care givers and family members want to know the wishes of their patient and loved one when the time of death is near. But make no mistake about it, some persons are advocating living wills as one step on the way to active euthanasia or doctor-assisted suicide.

WHAT ARE SOME OF THE PROBLEMS WITH LIVING WILLS?

1. The standard living will documents refer only to the termination of treatment.

Most living wills only allow you to designate that you want certain medical treatments withheld or withdrawn, and 'that (you) be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide (you) with comfortable care or to alleviate pain.'⁶ Some standard forms only allow you to say whether or not you want nutrition and fluids and whether or not you wish to donate your organs for transplantation.

The desire to donate your organs at death is a very personal decision and one that you should make freely and without coercion. And the decision to discontinue food and water is a very complex and critical issue in medicine. First, the provision of food and water is the most basic of care and cannot be characterized as an 'extraordinary measure.' Second, to cause a person to starve to death intentionally is unjust active killing, which is prohibited in the Bible.⁷ Third, euthanasia contradicts the role of the physician as healer.⁸ The Christian Medical and Dental Society has declared,

... we believe that physicians, other health professionals, and health care facilities should initiate and continue nutritional support and hydration when their patients cannot feed themselves. We are concerned that demented, severely retarded, and comatose individuals are increasingly viewed as 'useless mouths' (we reject this dehumanizing phrase). Rather than encouraging physicians to withhold or withdraw such patients' food and water, we encourage physicians to respond to God's call for improved physical, social, financial, and spiritual support of all vulnerable human beings.¹⁰

Furthermore, the Christian Life Commission has gone on record as officially opposing 'any designation of food and/or water as "extraordinary" medical care for some patients.'¹¹ An appropriate Advance Medical Directive should at least allow you both to specify the medical treatments you want maintained and the ones you might want discontinued. This leads to the second difficulty with the standard living will document.

2. Living wills may not be specific enough.

Even the best of the approved living wills do not allow for sufficient options or details regarding treatment. For instance, the standard living will document does not allow you to state under what circumstances you do or do not want antibiotic therapy.

[A patient] might desire penicillin for a painful skin infection but not a relatively toxic antibiotic such as amphotericin B for a probably fatal systemic fungal infection. Or, the patient may not want an antibiotic for a virulent pneumonia that will lead to rapid death but would prefer an antibiotic for an indolent

pneumonia that is not expected to result in death but is causing an uncomfortable cough and chest pain.¹²

Living wills do not allow the kind of specificity that most patient's care will demand even in the terminal stage of their illness.

3. Living wills are vague.

Phrases like 'life-sustaining procedures', 'treatments that prolong the process of dying', and 'there is no reasonable expectation of recovery from extreme physical or mental inability' are very common in living will forms. Other phrases and words like 'imminent death' and 'artificially prolong the dying process' are highly problematic and impossible to define with precision. Their meaning and application will differ from case to case and will probably differ even over the course of one patient's illness.

Note that the person(s) who will interpret these terms and make decisions for the patient is the physician (or two physicians in some states) and not necessarily the patient's family.

Because so much power—the power of life and death—is given to physicians through living will documents, and because it is impossible precisely to define some terms contained in living wills, alternative medical directives may be preferable.

4. A physician and patient are in a covenant relationship which demands consultation and negotiation. The physician promises to provide certain treatments under certain conditions, and the patient promises to comply under certain conditions. During the course of a 'normal' illness, the covenant is revised as a patient's condition changes. For instance, a responsible person does not say, 'Okay, doc, do whatever you want to do'. Rather, the doctor may say, 'Here are the treatment options. I think this is the best and recommend it. Are you willing to comply with the therapy?' The patient then may either comply, negotiate or refuse treatment.

The decision to discontinue food and water is a very complex and critical issue in medicine.

Living wills make a nominal effort at honoring such a covenant, but are often too rigid. Living wills usually do not allow for negotiation and revision of treatment decisions. That is not to say that living wills cannot be revised. But they can be revised only as long as you are conscious and competent. If you become unconscious or are in a persistent vegetative state, negotiation becomes impossible. Living wills are not the most flexible means of carrying out your wishes and respecting Christian values in the event that you become incompetent or unconscious.

WHAT ARE THE ALTERNATIVES TO A LIVING WILL?

1. Talk with your family about your values and wishes. Though the law is being tested at this point, it is still the case that most physicians will consult with and seek to honor the wishes of a patient's next of kin regarding medical treatment. At least one other person in your family (preferably several) should know what you think about life and death and what you want done or not done if you are near death.

2. Execute a Durable Power of Attorney for Health Care.¹³ This medical directive enables you to name a trusted relative or friend to make your medical decisions when you cannot do so for yourself. This includes your right to refuse treatment you would not want. The Durable Power of Attorney for Health Care allows you to

Living wills usually do not allow for negotiation and revision of treatment decisions.

designate someone as your 'attorney in fact,' and empowers him or her to make health care decisions for you. Your 'attorney in fact' does not have to be an attorney or doctor. He or she may be a spouse, relative, friend, neighbor or fellow church member. You should choose someone (1) who knows you well and shares your Christian values, (2) with whom you have discussed your wishes and (3) who is willing and able to serve as a decision-maker in what could be a very stressful time. Unless you otherwise specify, the document may also give your attorney in fact the power after you die to: (1) authorize an autopsy, (2) donate your body or body parts for transplant or scientific purposes and (3) authorize the disposition of your body for burial (which may involve cremation, unless you specify otherwise).¹⁴

Your local hospital administrator or attorney should be able to secure a Durable Power of Attorney for Health Care for you to review and explain it to you. If there is anything you don't understand in the document, you should ask for the assistance of a competent attorney.

3. If you are uncomfortable placing life-and-death decision-making on the shoulders of a loved one, or if you have no one who may serve as your attorney in fact, you may wish to sign a 'Will to Live'. The Will to Live differs from standard living wills in its strong presumption in favor of life. That is, the Will to Live instructs your physician(s) to do what is necessary to preserve your life 'without discrimination based on (your) age or physical or mental disability or the "quality" of (your) life' and rejects 'any action or omission that is intended to cause or hasten death'.¹⁶ Very simply, the Will to Live is a pro-life, anti-euthanasia alternative to a living will.

The Will to Live designates food and water as basic necessities and allows you to specify treatments you would want withheld or withdrawn under certain cir-

cumstances. The document also defines 'imminent death' as, when 'a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved, would judge that I will live only a week or less even if lifesaving treatment or care is provided to me . . . '.

4. Talk to your physician and have the Durable Power of Attorney for Health Care or Will to Live added to your medical records. The document is useless unless your family and physician(s) know it exists, and unless the doctors possess a legal copy of it. You might also talk to your pastor and give him a copy of your Durable Power of Attorney for Health Care or Will to Live.

5. Take a legal copy of your Durable Power of Attorney for Health Care or Will to Live with you should have to enter the hospital. The hospital personnel are required by law to ask you if you have a medical directive, and it would be wise to provide them with yours at that time, rather than completing whatever standard form they may offer. You are not required to have an advance directive.

Very simply, the Will to Live is a pro-life, anti-euthanasia alternative to a living will.

6. Remember, like the living will, the Durable Power of Attorney for Health Care does not become effective unless you become unable to make decisions for yourself. The Durable Power of Attorney for Health Care says, 'To ensure that decisions about my medical care are made consistent with these wishes and my personal values, I appoint the following person my attorney in fact to make health care decisions for me whenever I am unable to do so'.¹⁸ Likewise, the Will to Live becomes effective only when you are incompetent and your death is imminent.

1. Ezekiel J. Emanuel and Linda L. Emanuel, 'Living Wills: Past, Present, and Future', *Journal of Clinical Ethics* 1 (Spring 1990), p. 9.

2. John LaPuma, David Orentlicher, and Robert J. Moss, 'Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990', *Journal of the American Medical Association* 266 (July 17, 1991), p. 402.

3. *Ibid.*

4. Michael K. Whitehead, 'Whitehead: Living wills mean danger ahead', *Light* (January-March, 1991), p. 9. See also, Nigel M. de S. Cameron, 'Living Wills and the Will to Live', *Christianity Today* (April 6, 1992), pp. 22-24, and Sharon S. Mahone, 'Living Wills: Down the Slippery Slope?' *Journal of Christian Nursing*, pp. 4-9.

5. *Capital Punishment*, Nashville: The Christian Life Commission. See also Wayne House and John Howard Yoder, *The Death Penalty Debate* (Dallas: Word), 1991.

6. Tennessee Living Will, 1991.

7. For a more complete treatment of euthanasia and the withholding and withdrawal of treatment, see Franklin E. Payne, Jr., *Biblical/Medical Ethics: The Christian and the Practice of Medicine* (Milford, Mich.: Mott Media, 1985); John Jefferson Davis, *Evangelical Ethics: Issues Facing the Church Today* (Phillipsburg, N.J.: Presbyterian and Reformed Publishing Company, 1985); and Norman L. Geisler, *Christian Ethics: Options and Issues* (Grand Rapids: Baker Book House, 1989).

8. See the excellent treatment of this theme in Nigel M. de S. Cameron, *The New Medicine: Life and Death After Hippocrates* (Wheaton, Ill.: Crossway Books, 1991).

9. Duncan Vere, *Voluntary Euthanasia—Is There an Alternative?* (London: Christian Medical Fellowship Publications, 1971), p. 50.

10. Christian Medical and Dental Society, Medical Ethics Commission Statement, 'The Withholding or Withdrawing of Nutrition and Hydration', approved by the House of Delegates, May 3, 1990. Parentheses theirs.

11. Christian Life Commission of the Southern Baptist Convention, *Annual Minutes*, September 14, 1988, p. 44.

12. Allan S. Brett, MD, 'Limitations of Listing Specific Medical Interventions in Advance Directives', *Journal of the American Medical Association* 266 (August 14, 1991), p. 826.

13. It is important to distinguish the Durable Power of Attorney for Health Care from other durable powers of attorney. The DPAHC has nothing to do with your finances or estate. It is limited to power over your medical care alone. A durable power of attorney may be drawn up to cover both financial and medical matters in some states.

14. *Durable Power of Attorney for Health Care*, Legal Services of Middle Tennessee, 6/91, p. 1.

15. The Will to Live, may be obtained by sending a self-addressed, stamped envelope to: Will to Live Project, Suite 500, 419 Seventh St., NW, Washington, DC 20004.

16. *Durable Power of Attorney for Health Care*, p. 1.

Available in booklet form from The Christian Life Commission of the Southern Baptist Convention, 401 Commerce, #550, Nashville, TN 37208-3696

LIVING WILLS—THE ISSUES EXAMINED

A Briefing Paper from CARE, London

WHAT IS A LIVING WILL?

A 'Living Will' (LW) is usually a document in which the person requests that various kinds of medical care, which may be specified, be taken or not in the event that he/she becomes incapable of requesting them as a consequence of being seriously ill or injured.

Additionally or alternatively, a person may appoint another individual (sometimes referred to as a health-care proxy) to act on his/her behalf in deciding what medical treatments are appropriate if he/she should become incompetent (*i.e.* unable to communicate their wishes). This person has the task of using his/her knowledge of the incompetent patient to make decisions that the individual themselves might make, if able to do so.

Either of these two approaches (LW and proxies) may also be known as an 'Advance Directive' since they can be used to give advance directions for the kind of medical care an individual would like to experience if he or she becomes incompetent.

LEGAL POSITION

In this country, neither legislation nor case-law permits proxy decision-making in matters of adult health care. However, the situation is different in relation to LWs for, although there is no legislative provision for these documents, case-law indicates that they may have legal effect.

The courts have long held that a competent person can validly give or withhold consent to treatment. In a recent case (concerning the refusal of a blood transfusion by a Jehovah's Witness) they have indicated that a patient can, while competent, validly give or withhold consent to treatment during a future state of incompetence. The courts would, however, wish to be assured that certain conditions had been met *e.g.* that the patient understood the nature and effect of the treatment, that they had not been unduly influenced by another party, and that they were properly informed.

It is therefore likely that the courts will, if specifically faced with the question of the legal validity of LWs, declare them legally effective if they satisfy those conditions.

There are, however, limits to the legal effect of living wills: a living will can only permit a doctor to treat or

prevent a doctor from treating; it can never compel him to treat.

In the USA there has been Federal legislation in effect in every state since December 1991 regarding Advance Directives.¹ This is known as the Patient Self Determination Act (PSDA). Among other things, it requires that patients receiving medical care at an institution, which receives Medicare or Medicaid, must receive written information about their rights to formulate some form of Advance Directive and must be asked if they already have one.

WHY WOULD SOMEONE WANT A LIVING WILL?

In recent times the increasingly sophisticated technological advances of medicine have resulted in treatments for previously untreatable or incurable disease. Even when a complete cure is not possible life may be prolonged sometimes for a considerable time. At the same time as these developments, and sometimes as a consequence of them, medical care has become more institutionalised. The giving of medical care has increasingly been transferred from the more familiar general practitioner to more remote hospital doctors.

This has inevitably undermined the basis of the relationship between the individual and those treating him/her. It is no longer built on familiarity with an individual. Indeed in recent times that familiarity with the 'family GP' is being lost. This may, at least in part, be a result of the increased mobility of the population which does not allow the development of such long term relationships. Thus individuals find they must rely on a general confidence in the medical profession as a whole. That confidence can be further undermined by the extent to which different treatments are now possible for the same condition, and doctors do not always agree about what is best.

The anticipation of possible chronic illness or severe disability can lead to a fear of increasing dependency on others. Combined with the erosion of confidence in the medical profession generally to act appropriately, this has led to the desire to retain some control of our destiny, even when we are no longer competent to do so. The result has been a growing demand for LWs.

BIBLICAL PRINCIPLES

Understandably, the expectation of suffering can result in a fear of a future in which unknown hardship may be experienced. As individuals we have an inherent right and responsibility to make decisions and choices about the way we live our lives. The idea of exercising our freedom to choose by drawing up a LW, in order to avoid such potential hardship, can appear attractive. However, as Christians our choices must be instructed by the laws given to us by God. Because we are made in God's image (Gen 1:27) we are prohibited from taking life (Ex. 20:13; Mt. 5:21). Thus life is sacred and is a gift from God (Psa. 139:13ff).

We are not free to choose to terminate the life of another individual, nor to ask anyone to do this for us, either in the present or at some time in the future designated by a LW. Indeed, there is no Biblical justification for terminating our own lives. There are three suicides reported in the Bible: Saul (1 Sam 31:4), Judas (Matt. 27:5) and Abimelech, who was helped by his servant (Jud. 9:54). Although none of these are specifically condemned, they all occurred as a consequence of the perpetrator having chosen to take actions which were clearly in rebellion to God.

This cannot of course negate the reality of suffering. Throughout the Church's history, Christians have struggled to understand the meaning and mystery of suffering. Suffering, *per se*, is not God's purpose for people (Lam. 3:32-36). However, human history tells us that suffering is inevitable in almost every individual's life. Exercising our responsibility to make choices about our lives may directly result in suffering, as it did for Jesus (Phil. 2:5-8).

Ultimately every experience in human life, either of ill or of good, arises from the curse of mortality (Gen. 3:14-19) or the providential goodness of God in relieving its effects. However, scripture is clear that most of an individual's suffering is not the result of specific sin (John 9:1-14; Luke 13:1-5).

We often see sickness as harmful and bad. Indeed, Christ was frequently moved with compassion to heal the suffering of those he met (Matt. 11:4-6, 9:18-38; Luke 4:40, 5:17). It is clear that, as his followers, we too are expected to do all we can to bring relief to those in physical pain and need (Matt. 10:8, 25:37-40; Luke 9:6; Ja. 5:14-16). That is why many Christians historically have been in the forefront of developing medical treatments and techniques to control pain and alleviate suffering.

However, it is also true that physical suffering can show us our limitations, give us a clearer perspective on life and eternity, teach us more fully about the love and forgiveness of God, refine our faith, make us more Christlike and produce perseverance and character (2 Cor. 12:7-10; 1 Pet. 1:5-7; Heb. 12:11, Rom. 5:3-5; Psa. 119:71). Indeed Christ's purpose in participating in human life and suffering was not primarily to eliminate it from our experience in this world but to win for us an external redemption which will be fully realised in the world to come when there will be no more pain or suffering (Rev. 21:4).

The Bible clearly exhorts us to commit our lives to the Lord and trust him for our future (Heb. 13:6, Phil. 14:6-7; John 14:1). This does not preclude the possibility of suffering. Job experienced sickness, bereavement and poverty. With the insight of scripture we know that these were allowed by God because of Job's virtue (Job 1:8) but there is no evidence that Job ever knew this, even after his fortunes had been restored. To Job, as to us, God offers himself as the sole guarantee of his goodness. We must take him on trust.

WITHHOLDING OR WITHDRAWING TREATMENT

Although we are clearly prohibited from deliberately terminating another individual's life there is no Biblical justification for sustaining life for as long as possible at whatever cost. For the Christian, death has been transformed into the gateway to glory by Christ's death and resurrection and is to be anticipated as such (Phil. 1:21).

There may be times when withholding or withdrawing a treatment is appropriate and times when it is not. Some treatments which are given with the patient's best interest in mind may carry a risk of shortening lives, *e.g.* high doses of painkillers.

The practice of 'good medicine' has always included striving to relieve suffering and giving treatments which are expected to benefit the patient. In recent years there have been tremendous advances in treatments to control pain and alleviate distressing symptoms. Crucial to this has been the emergence of the hospice movement where many of these treatments have been developed and become part of the excellent care provided to each individual hospice patient.

What is important is the *intention* behind giving, withholding or withdrawing a treatment. If it is to make the patient as comfortable as possible by relieving suffering this is appropriate medical treatment—if it is to deliberately bring about death it is not. For example, a terminally ill patient suffering from cancer may be given a high dosage of a morphine based pain-killer in order to control the individual's pain—even though this may risk shortening the patient's life. This is appropriate medical care. However, it would not be appropriate to administer a drug with the deliberate intention of ending the patient's life. This was the issue in the recent case of the doctor who injected his elderly patient, who was suffering with rheumatic arthritis, with potassium chloride.

WHAT DOES THE BRITISH MEDICAL ASSOCIATION SAY?

The British Medical Association (BMA) consider that LWs may have definite benefits in acquainting doctors with a patient's treatment wishes. It is easy to see how this can appear very attractive when the patient is unknown to the doctor who is called upon to treat him/her. It could, for example, help to decide what treatments would seem overburdensome to the patient and therefore which he

would decline if competent to do so. However, the BMA does not want to see legally enforceable LWs since they may request treatments which are completely inappropriate or indeed illegal *e.g.* euthanasia.²

PRACTICAL DIFFICULTIES IN IMPLEMENTATION

In some circumstances a LW may help to inform a doctor of a patient's wishes. However, there are a number of significant problems with the implementation of any formal declaration of a patient's wishes in advance, such as a LW. The most fundamental of these is with those LWs which effectively require the doctor to satisfy a patient's earlier suicidal wish—which can never be right. Some other issues are detailed below.

1. Timing

How do we decide—and who decides—when the conditions set out in the LW are to take effect? There must be a clearly identifiable 'trigger event' (*i.e.* something which causes the requirements of the LW to be acted upon). Reasonably, this could be expected to be either the onset of incompetence or the occurrence of some other event, such as a treatable infection like pneumonia, once incompetence was established.

But there must be agreement by everyone involved—medical care-givers, relatives, *etc.*—that the trigger event has occurred. The major difficulty here is in the definition of incompetence, whether it is transitory or permanent, and whether the patients's wishes would remain the same irrespective of this. A patient may be confused due to an underlying disease. If this other illness is treated the confusion may be reduced. Even deterioration into chronic confusion in the elderly may be reversible *e.g.* depression, vitamin deficiencies, underactive thyroid.

To be sure of implementing the LW according to the original wishes of the patient, it would be necessary to have a demarcation of an unequivocal trigger event which would be almost impossible.

2. Informed Decision

If the main concern behind LWs is to give patients more control over their medical treatment, the main difficulty they raise is that patients can almost never know enough ahead of time to be able to take an informed decision at all.

An individual can never foresee the precise situation which may face him/her at the time of implementation. Advances in medical technology may mean that what is inconceivable today may be achievable tomorrow. Thus what may seem a suitable trigger event at the time of writing a LW may no longer be so at the time of implementation.

By virtue of training and experience, a medical practitioner might be expected to be more competent to make an informed decision about the best treatment in a given

situation that the majority of individuals who might draw up a LW. Thus it would be bizarre and unethical to require a physician to adhere to the stipulations of a LW which did not accord with his/her skilled opinion of what would be in the best interests of the health of the patient.

3. Changes of Mind

An individual cannot foresee what changes of attitude he or she may experience with changed circumstances. Disabled people are commonly more satisfied with their life than many able bodied people would expect to be with the same disability. The healthy do not choose in the same way as the sick.³ To implement a LW executed by a healthy individual at a time when that individual is sick would preclude changes of mind and could result in the death of an individual who would now wish to live.

It is not unusual for individuals to alter their opinions about what they would wish to happen to them at the end of life. For example, a year before he died, the writer Jeremy Warburg expressed a wish for euthanasia but subsequently poignantly described his desire to live life to its end and not to be killed prematurely. 'Astonishingly I don't want to take or lose my life. Glad there is no euthanasia bill through Parliament. If there were I would be even more suspicious of the people who look after me.'⁴

4. Incorrect Prognosis and Diagnosis

The trigger event chosen for the timing of the implementation often requires the doctor in attendance to confirm that there is no hope of recovery and, in many circumstances, that the illness will result in death very soon. Indeed prognosis, *i.e.*, the prediction of the progress of a disease, can only ever be the best possible guess since the outcome is in the future. The human body is not like a computer or a machine for which a series of actions leads to an inevitable result. There are many instances of incorrect diagnoses and prognoses⁵ the effects of which cannot be corrected once the patient is dead!

5. Cancellation

In an attempt to cater for changes of mind 'late in the day' most LWs include a clause that states that they may be revoked at any time and this need not be in writing. How could a document which may be revoked by a private conversation with a single individual and without witnesses ever be legally binding?

6. Care Facilities

In drawing up a LW many individuals are seeking to avoid becoming a member of a marginalised group such as the confused elderly, the terminally ill or the severely disabled. Often medical care and facilities for these groups attract little funding. Fear of becoming recipients of services they feel are poor and/or unlikely to be improved may form part of the motivation for drawing up a LW.

Those who are already members of these marginalised groups may feel pressured into completing a LW themselves in an attempt to avoid being what they perceive as an 'unacceptable burden' on relatives, carers and society in general. Do we, as a society, really want individuals to feel obliged to make decisions which could result in death, because they fear they will be an inconvenience to others?

7. Euthanasia by the Back Door?

The strong support given to the use of LWs by the Voluntary Euthanasia Society (VES) is very concerning. It demonstrates that it is this Society's intention that the use of these documents should be the first step toward the legalisation and practice of euthanasia—the deliberate termination of an individual's life by another person.

Many LWs sanction the withholding of food and water. Professor David Short MD FRCP FRCPE has said: *'Starvation leads slowly to inevitable death so there would undoubtedly be "compassionate" demands that the patient should not be allowed to linger but should be given a lethal injection . . . it would be a step into the realm of euthanasia.'*⁶

LEGALLY ENFORCEABLE LWs

The difficulties of implementing LWs would only be compounded if Parliament passed an Act making them legally enforceable documents. Doctors may find themselves bound to carry out their stipulations even when the course of action is not longer in the best interest of the patient nor likely to be in accord with his/her intentions.

For instance, the particular event stipulated by the individual as the trigger to implement a LW may occur in a set of circumstances radically different than those anticipated by the patient. Alternatively, technological advances may have equipped the physician to do far more than the patient considered possible at the time of writing the LW.

Additionally, an incorrect diagnosis may have led an individual to request certain measures which a correct diagnosis would make unnecessary or even harmful. A legally binding LW might result in a physician being unable to alter treatment measures without risking legal action.

Legislation which makes LWs legal documents will add nothing to medical practice and may result in poorer care for the patient.

WHAT ARE THE ALTERNATIVES?

Patients are entitled to expect to receive compassionate and humane medicine. LWs can seek to provide individuals with the means to ensure that they will not receive inhumane medical treatment or be subjected to over-aggressive medical practices which merely prolong dying. However, if such futile medicine is being practised it is surely more appropriate to encourage medical practitioners to practice 'good medicine' than to place the onus for this on the public.

Therapeutic measures directed at symptom control, and general well-being rather than prolongation of life at all costs are available. The Hospice movement in the UK, which had its origins as a Christian response to caring for the dying, has made fundamental advances in such medical treatments which are sometimes collectively known as 'palliative care'. A recent World Health Organisation report states that 'the quality of life and comfort before death could be considerably improved through the application of current knowledge on palliative care, which is all too often ignored . . .'.⁷ Palliative care is increasingly becoming recognised as a medical discipline in which doctors can become qualified and skilled. A number of units practising hospice style palliative care exist in some NHS hospitals. Where further improvement is necessary in British hospitals we must make every attempt to give better care and to ensure that compassionate and humane medicine is available to patients irrespective of whether they have requested it in a LW.

ACTION

- **Pray**—Bring to God in prayer the unnecessary neglect of the weak and vulnerable in our land—elderly, terminally ill and disabled people. Pray that God will move in our nation, and particularly in the hearts of his people, that we would pray and think and act to bring about a more caring society.
- **Inform** your church so that Christians will be aware and able to take action.
- **Make** your views known to your Member of Parliament by writing to him/her at the House of Commons, Westminster, London SW1A 0AA (Tel. 071-219 3000).
- **Contribute** to the public debate. Make the most of media opportunities, e.g. the letter pages of newspaper and magazines, radio-phone ins, television phone-in polls. Stress the more humane alternatives to the problems LWs seek to address.
- **Care**—Contact your local hospice. These establishments rely on volunteers to be able to continue to function since they receive limited NHS funding. For details of hospices in your area contact the Hospice Information Service at St. Christopher's Hospice, 51 Lawrie Park Road, Sydenham, London SE26 6DZ (Tel. 081-778 9252).

1. Fenella Rouse *Patients, Providers and the Patient Self Determination Act*, in *Practicing the PSDA Special Supplement Hastings Center Report* 1991 21 (5) S2.
 2. British Medical Association Statement on Advance Directives, May 1992.
 3. *British Medical Journal* 1985 291 1620.
 4. *A Voice at Twilight* 1986 Jeremy Warburg.
 5. *British Medical Journal* 1987 295 318—*Patients with terminal cancer who have neither terminal illness nor cancer*.
 6. Professor David Short MD FRCP FRCPE in a speech given in London 24 July 1992.
 7. Report of a WHO Expert Committee, 1990. Cancer pain relief and palliative care: Technical Report Series 804.
- Further copies of this article in pamphlet form available from Christian Action Research & Education 53 Romney Street, London SW1P 3RF.

A statement by HOPE (Healthcare Opposed to Euthanasia)

EUTHANASIA AND MEDICAL PRACTICE IN THE UK

INTRODUCTION

Over recent years, attitudes have changed towards the role of the medical practitioner in dying and death, and in sickness and health. High-technology medicine has stirred up intense media curiosity in what had previously been the private world of the doctor-patient relationship. There is a demand that medical decisions be publicly justified and, for better or worse, the fear of litigation has driven many doctors to rely increasingly for justification on the wishes of the patient.

Public mores and values are changing too. Religious traditions are no longer alone in offering a framework for answering the big questions of 'who?' and 'why?' we are. Secular world views have changed the framework in which many doctors make medical decisions: now man is at the centre. He alone gives meaning, establishes value and determines when life begins and ceases to have significance.

The result of such a rapid shift in public values and technical prowess is a questioning and breakdown of longstanding prohibitions. Historically, such times have provided society with the opportunity for creative thinking, a chance to find new answers to old problems. On the other hand, as old safeguards are jettisoned, society may well lose its way, if new-found freedom gives way to anarchy. It is within this kind of social context that the question of euthanasia is raised.

WHAT IS EUTHANASIA?

Voluntary euthanasia involves a doctor killing a patient at the patient's request, for what we may term here as 'euthanasiast' reasons. What these reasons are will become clear in the course of this booklet.

The proposal that killing should become part of standard medical care is an obvious challenge to medicine's traditional ethic—do good to the patient, not harm. Yet proponents of euthanasia would argue that the very notions of 'good' and 'harm' should change—that in this context, to kill should be seen as a good and proper aim of medical treatment.

We need to be clear that in defining cases of euthanasia, it is the doctor's *Intention* which is of central importance. Terms frequently used such as 'active' and 'passive' are unhelpful, unless we first ask 'did the doctor *intend* to kill his patient in this particular case?' It is clear that intentional killing can take place in both 'active' and 'passive' categories; by the deliberate omission of treatment as

much as through the administration of a lethal dose. It is equally important to recognise that where the intention is not to kill the patient—even though the patient may die—the issue is not one of euthanasia.

In this paper we argue that euthanasia should never become part of standard medical care. However we have come to this view only after much discussion and heart-searching. We recognise that euthanasia is a highly personal and sensitive issue, and that dying has all too often been a bad experience for patients and their families. We believe that it is our task as doctors and nurses to ensure that each person's death is as 'gentle' and 'easy' as possible. However, we remain convinced that the path offered by euthanasia is not what it seems, and that it is not the right way forward either for the individual or for society.

THE CASE FOR EUTHANASIA

The following story was heard from a Dutch doctor at a recent (1990) conference of 'Right to Die' societies in Holland.

'Mr. A. K., an elderly gentleman, was admitted to hospital with abdominal pain. In the bed next to him was an old man who was being attended by his doctor. He was dying, and he knew it. "No", Mr. A. K. heard the doctor say, "you're not going to die, you're in hospital: we've got the equipment. We'll see that you're alright—you can't die yet. The engine may be broken but we can re-build it! We simply have to pass a tube in your stomach." "But I don't want a tube in my stomach" said the old man. Mr. A. K. looked away. He heard the conversation continuing. "I want to live like a man not . . .". "The tube will only be there for three days", said the doctor, "then you will have surgery. You will be alright." His condition got worse. "But doctor, I know I am dying," the man said again. But no one was listening. They passed the tube into his stomach. Some time later, Mr. A. K. awoke to a loud noise: the old man was having a heart attack. "Quick," shouted the doctors, "resuscitation." For a while, the old man came round. "I'm dying", he told the doctors again. "Let me go . . ." he pleaded. When Mr. A. K. awoke the next morning, the old man was dead. His tubes lay at his side and in his hand, a crumpled note. Quite simply, it read: "Death is not the enemy, doctor, but inhumanity is."'

Most of us will have heard stories like this, where the inability of doctors to recognise that death is now close and inevitable has led to mindless or meddlesome medi-

cine. And it is these stories which have led some people to advocate euthanasia—as the only way to guarantee a ‘gentle and easy death’.

PRO-EUTHANASIA CONCERNS

The British Humanist Association and the Voluntary Euthanasia Society are two groups promoting voluntary euthanasia.

‘Humanists are sympathetic to voluntary euthanasia. By this we mean helping people to die painlessly if their lives have become hopeless, with no prospect of relief before death; and if they wish to die. Both these conditions must be rigidly adhered to.’¹

and from the Voluntary Euthanasia Society:

‘The main objectives of the Society are to secure the enactment of the 1969 Voluntary Euthanasia Bill by Parliament. This would authorise doctors to give patients euthanasia when they wish it, provided: a) the patient has signed an appropriate declaration at least 30 days previously, b) two doctors, one of consultant status, have certified in writing that the patient is suffering from an incurable condition likely to cause him or her severe distress or to be incapable of rational existence.’²

The aim of groups campaigning for euthanasia is to see a change in the law to enable doctors to kill their patients without fear of prosecution.

In public debate, two main concerns are put forward:

- 1) that we need to address the suffering of the sick and dying
- 2) that people have the right to decide the manner and timing of their death—a ‘right to die with dignity’.

Indeed, the ‘right to die’ has become the catchphrase of the euthanasia movement. At its heart lies the notion that we should be allowed to make decisions concerning our own lives which do not affect those around us—in other words, the issue of ‘autonomy’.

EUTHANASIA: PUBLIC ACT, PRIVATE CHOICE?

On the face of it, arguments from autonomy—which say that it is for the individual to make decisions about his/her own medical treatment—are the most compelling and most likely to weigh heavily with doctors and patients in any discussion of voluntary euthanasia. On reflection, however, we believe that this good medical principle is much abused in the euthanasia debate.

Advocates of euthanasia stress that the decision to die is a purely private one, which affects none but the decision-makers themselves. It is argued that this is simply the exercise of autonomy; the patient’s right to decide which medical treatment is right for him/herself.

Laying aside for the present the claim that a request for euthanasia is made freely, and ignoring the implication

that killing might be a legitimate form of treatment, we are left with the question: is the request for euthanasia an expression of patient choice which doctors need to follow? Or put another way, is the refusal to agree to a patient’s demand for euthanasia simply a case of overbearing paternalism, and one that modern doctors need to redress?

To help us examine these questions, let us look at the following examples. First, let us consider the case of an elderly gentleman who suffers from a variety of complaints which we would broadly attribute to ageing: partial loss of hearing, poor mobility, periodic incontinence. In addition, however, he lives alone, in very poor conditions, and has no visitors. Weakened by a chest infection, the old man indicates that he wishes he were dead. On a repeat visit from his GP, the same request is made. After the third request, the doctor feels he has to do something: he agrees to help the old man to die.

Consider now the case of an active young man, an accountant, who visits the same GP and requests euthanasia. The doctor can find no sign of illness but on discussion, discovers that the young man has recently been divorced and has lost his job. He refuses this man’s request for euthanasia and refers him for counselling.

These examples show that voluntary euthanasia is not simply about a patient expressing a request which the doctor must follow. In both cases, the doctor had to come to an independent judgment (one regardless of the patient’s wishes), not based in any specific sense on medical factors, about the probable quality of the patient’s future life. In the case of the elderly gentleman, social and personal factors such as poverty and loneliness probably ranked high among the considerations taken into account by the doctor in agreeing to the euthanasia request. On the other hand, youthfulness, health and good earning potential would have been significant in assessing the younger man’s ‘quality of life’.

In reality, the practice of euthanasia would place upon the doctor an impossible burden of weighing and balancing many factors. Few would be purely medical and some would be impossible to assess with any degree of accuracy. The doctor would have to judge whether a given life was ‘worth living’ or whether the patient would be better off dead.

How can any doctor make such a decision about his or her patient? The usual riposte—to say that the doctor does not make that choice but simply does the patient’s (or his relatives’) bidding, is clearly not the case. As we have seen, doctors do not kill patients merely because they request it. They could only do so if they considered their patient’s life a hopeless one.

Euthanasia would force healthcare professionals to make life and death decisions about the worthwhileness of patients’ lives. What the consequences of such a move might be, we must now consider.

JUSTICE AND HUMAN RIGHTS

We believe that over time, the legalisation of voluntary euthanasia would adversely affect the human rights of us all.

The basis of our social system, upon which our system of justice is based, is that human beings have value and dignity (and so warrant respect) simply in virtue of the fact that they are human. Any proposal to discriminate between human beings on the grounds that some lack worthwhile lives will inevitably be subjective and therefore arbitrary. As we have noted above the practice of euthanasia involves medical professionals making just that sort of arbitrary distinction between patients, some of whom would be seen to have an 'acceptable' quality of life, others not.

Of course the whole notion of a 'worthwhile' life (as an aid to medical decision-making) is one that some philosophers are keen to introduce. Baroness Warnock recently made a speech on 'the value of life'. It was reported as follows:

The real issue, she contended, was whether society was entitled to value human life non-uniformly—giving more value to some lives than others. She said it was difficult to value quality of life for someone else, yet they (doctors, relatives) had to do it unless they were committed to the view that all humans are equal, simply because they were human.³

In Holland, where euthanasia is openly practised, philosophers, psychologists and doctors are already deciding who should die on the basis of an 'acceptable' quality of life. Note that in this instance, it is not just voluntary but non-voluntary euthanasia which is being proposed.

In 1985, a State Commission on Euthanasia recommended that it should not be an offence for a doctor to kill a patient who was unable to express his wishes, and who had irreversibly lost consciousness, provided that treatment had been suspended as pointless.⁴

Where there is arbitrariness about who is treated, there cannot be justice. Where basic human rights and the protection of the law are recognised only when there is a certain quality of life, how will we protect the weak and vulnerable—the very people whose care and concern should be the aim of our profession? Above all, how would we prevent voluntary euthanasia from becoming non-voluntary or involuntary euthanasia along the way? Supporters of euthanasia claim this could never happen. We believe it would, and statistics in a recent Dutch Ministry of Justice Report confirm this, showing that 1,030 patients were killed without their 'explicit and persistent request'.⁵

PRESSURES TO KILL AND THE 'STRICT SAFEGUARDS'

We have seen that the justification of the killing involved in voluntary euthanasia contains the judgment that a patient's quality of life is so poor that their life is 'no longer worth living'. But what makes someone's life worth living? How will doctors evaluate? For most

people, family relationships are crucial in giving life meaning and value. The loss of spouse or children often takes this away for months and at times, years, leaving those left behind with a sense of loss that can ebb and flow with the seasons. Would we consider euthanasia for the octogenarian whose spouse has died, who is lonely and has no friends?

Social isolation, poverty, lack of family and friends; these are the realities which will influence a patient's fight against sickness or disease. These are all factors which determine the 'worthwhileness' of each of our lives—in sickness and in health. The impact of terminal illness on a person's life cannot be judged in a medical sense alone. As we saw in the examples [Euthanasia: Public act, private choice?] doctors who administer euthanasia are obliged to consider non-medical factors in establishing their patients' 'quality of life'. And could we face a situation where euthanasia was performed because, say, the patient has bad housing or no friends?

In media debate on the issue, those who support euthanasia decry these possibilities as unrealistic and over-emotional. We would ask you therefore to consider the following interview from Holland, where euthanasia takes place freely, in which a British academic lawyer is interviewing a leading euthanasiast doctor.

Herbert Cohen, a GP, is one of Holland's leading practitioners of euthanasia. He has said that he would be put in a very difficult position if a patient told him that he really felt a nuisance to his relatives because they wanted to enjoy his estate. Asked whether he would rule out euthanasia in such a case, Dr. Cohen replied: 'I . . . think in the end I wouldn't, because that kind of influence—these children wanting the money now—is the same kind of power from the past that shaped us all.'⁶

The 1984 Report of the KNMG (Royal Dutch Medical Association) concluded that it would legally be possible to kill people because they are 'tired of life'. How has this situation in Holland come about? Is it a peculiar exception? Let us look at what some doctors are already suggesting in this country.

In a recent letter to the *British Medical Journal*, a psychiatrist based in the Midlands argued for euthanasia on behalf of some of his psychiatric patients. What are his criteria? Those patients in deep 'distress' due to 'substance abuse' or 'personality disorder', those who—in his own view—face a 'lifetime of desolation' should, he argues, be considered for euthanasia.

'Sir, Dr. Michael Phelan's personal view illustrates some important discrepancies in attitudes to death across the artificial divide between physical medicine and psychological medicine.

Passive euthanasia for the chronically physically ill is an acceptable subject for debate in medical circles. Yet euthanasia for chronic psychiatric disorders does not appear in the index of standard books on psychiatric ethics or suicide, the nearest concepts being balance sheet suicide and rational suicide.

The only exception to psychiatrists' evasion of

passive euthanasia is in patients with senile dementia, who may be deprived of active treatment for physical complications such as chest infections. Yet these people do not necessarily have a reduced life expectancy: the only justification is that their illness is organic rather than functional—a highly dubious dichotomy which was decried almost a century ago. The suffering of dementia is probably slight compared with that of the small minority of young, chronically mentally disordered persons whose distress proves intractable, often due to concurrent if not primary personality disorder or substance abuse, or both, and who face a lifetime of desolation. Such people are understandably those most likely to take their own lives. Surely this small group—once thorough, appropriate treatment has failed—should be allowed the peace of death at their own hand without guilt on the part of themselves or their doctor, if that is their unwavering choice?

Such decisions can be regarded as rational; even an apparently self-defeating act may represent the only opportunity for the powerless to exercise their will in an oppressive and alien world. In Japan ritual suicide is socially acceptable and is regarded as a final pathway to mastery and self esteem. Our Christian heritage has left us morbidly prejudiced against suicide, illustrated by a long history of punitive legislation. Now that we live in a multicultural society attempting to end prejudice against mental affliction and to maximise quality of life, psychiatrists should seek parity with other doctors including being free to discuss death with dignity and the ethics of euthanasia. When patients say they would be better off dead they may sometimes be right.⁷

Pressures to kill and doctors' differing views on what makes life acceptable and worthwhile mean that the reasons for administering euthanasia grow ever broader once euthanasia is openly practised. What is unacceptable today is commonplace tomorrow. We lose our boundaries; the worst fails to shock. Where doctors let go of the fundamental prohibition against killing their patients in any situation, there remains no ultimate barrier against administering euthanasia to all.

We believe therefore that all talk of 'strict safeguards' is at best naive and at worst a smokescreen created simply to encourage a change in the law.

ECONOMIC PRESSURES FOR EUTHANASIA

The legalisation of voluntary euthanasia opens up the medical profession to all sorts of competing pressures. The rationale that claims respectability for killing people who lack 'worthwhile lives' poses an obvious threat to those groups in society who may be viewed in that light. Indeed, the cost of care is a major factor motivating some people to take a sympathetic line towards euthanasia.

In a recent article in the *British Journal of General Practice*, a consultant geriatrician made the case for euthanasia on social and economic grounds.

'Modern families still try to look after their old people, but increasing longevity is making this more difficult. There is a finite ability of populations, however wealthy, to support dependent members. Resources provided to look after old people must necessarily be subtracted from those available for the other, still more important, dependent group, the children, with potentially disastrous results in under-funding of social support in education. The socio-biological theory of inclusive fitness emphasises the importance of the ways in which family ensure their genetic survival, even if this involves sacrificing their own interests, and occasionally their lives. Many old people do not wish for further longevity after they have become too disabled to be of service to their families and would prefer to see limited resources used for the young.'

The article then goes on to discuss the Living Will, which the author says will help families make decisions for those 'who are unable to decide for themselves' what treatment they should have. She adds 'this should include withholding or withdrawing life support and in certain circumstances, active euthanasia'.

The author's thesis depends on her assessment of the economic situation.

'To expect that we can pay proper wages to sufficient nurses to look after thousands of patients with Alzheimer's or cerebrovascular disease in the future is a dream . . . however, community care is unlikely to be either realistic or cheaper.'

Therefore, the author argues that families as a whole should be able to decide what happens to their elder members so that they can free resources to care for their younger members.

'Until now the greatest benefit of the National Health Service has been its ability to apportion its resources fairly amongst the whole population. We should do everything we can to see that this system continues, but we cannot do it without being realistic and without making sacrifices. It may seem ludicrous to compare our society with that of the Yakuts but ironically our very success is re-creating the battle for resources which determines the behaviour of primitive tribes and which demands similar solutions. We cannot expect to enjoy unnatural life unless we are also prepared to accept unnatural death.'⁸

It is clear from the article that the author seeks to justify not only euthanasia but also non-voluntary euthanasia as well—that is, killing without the patient's consent. Yet with changes in the NHS putting pressure on all health-care institutions—the question of 'who should care?' can all too easily become 'why care?' and 'should we care?' It is true that selective application of therapies is a useful measure against resource waste; but, once justified on that ground, it becomes applied to resource expenditure upon proper and justifiable therapies. The option to kill

will readily provide an easy and acceptable solution to a heavy economic burden.

PAIN AND SUFFERING

We stated at the outset that one of the central concerns of the pro-euthanasia groups is that people should not suffer needlessly. They argue that legalisation is necessary for those people in 'intolerable suffering' and illustrate their case with a story of someone known to them.

Yet we have seen [Pressures to kill . . . and Economic pressures . . .] that the concept of 'suffering' is unworkable in law. We have looked at cases from Holland, where the 'strictest guidelines' are in force, and found that 'suffering' can and does mean almost anything.

But what about physical pain? Some of us will remember the pain our own relatives (and patients) suffered in their sickness and death, and many such illustrations form the backbone of pro-euthanasia support. Yet the hospice movement has shown that now pain can be eliminated or eased considerably in all cases with the proper administration of drugs and other treatments. The World Health Organisation recognised this recently in its Technical Report 804, when it said: 'there is no need for patients to suffer prolonged and intolerable pain or other distressing symptoms'.

FREE CONSENT: REAL OR UNREAL?

The assurance that consent would be given freely is a crucial point in the case for euthanasia. Few would seek at present to argue publicly that euthanasia should be administered where consent has not been obtained (non-voluntary euthanasia) or against patient wishes (involuntary euthanasia). Therefore we must try to assess just how effective the role of 'consent' would be in protecting patients (and doctors) from error and abuse.

Those with experience in healthcare recognise the power doctors and other staff have in influencing patient decision-making. The presentation of information concerning an illness and its prognosis can in itself bring hope or despair. Psychologists recognise that in highly constrained situations vulnerable groups (the elderly, the sick) exhibit compliant behaviour, and readily comply with the wishes of the dominant group. On the one level, this suggests that professional staff who raise the option of euthanasia with a patient are giving a powerful signal to that person, namely, that their life is not worthwhile, that others consider the person would be better off dead.

Most elderly people are sensitive to the suggestion that they are a burden to friends or relatives. It is not only doctors who would be in a position significantly to influence the 'free' consent to die. From our experience we are sure that many sick people would opt for euthanasia rather than allow their loved ones to spend large amounts of time and money caring for them. Thus euthanasia would be requested—not to relieve the patient's own suffering, but to release others of the 'burden' of having to care.

All decisions are made in a context. Euthanasia would allow too many people to be killed, on the face of it 'at their own request', because of burdens and pressures on the people around them. Instead of society and the government taking hold of their responsibility to change the living conditions of many sick and elderly people—to provide proper support for primary carers, to make principles of good palliative care a mandatory part of all healthcare courses—we fear that legalised euthanasia would undermine the will to change, since a cheaper, easier option would already be in place.

Of course there is also the fact that patients frequently change their minds, and a seemingly persistent low mood can lift for a host of reasons.

Mr. D. L., a divorcé aged 52, developed jaundice in July 1990. A laparotomy in August confirmed carcinoma of the head of the pancreas, and necessary by-pass surgery was undertaken. He was noted to have liver secondaries. The post-operative course was complicated by an intra-abdominal abscess which delayed the start of a course of chemotherapy.

Meanwhile he left hospital to be cared for by close friends who lived nearby. However, when they went on holiday a few weeks later he returned to his own home and began drinking heavily. He neglected himself and soon was in a very poor condition. This pattern continued even after the friends returned from holiday and invited Mr. D. L. back into their home.

After the first pulse Mr. D. L. declined further chemotherapy. He became abusive, due to the heavy drinking bouts, and suffered intractable abdominal pain. He was referred to the hospice late in October and was seen as an out-patient. The next day he was admitted for an indefinite period. The consultant physician commented on his admission that 'It seems most unlikely that Mr. D. L. will return to the care of his friends'.

Both in open clinic and after his admission Mr. D. L. said that he simply wished to be left alone and to 'curl up and die'. He wanted an injection to finish things off but 'nobody will do that for me'. He remained withdrawn and was verbally aggressive at times.

The pain was readily controlled with long acting morphine tablets (30mg twice a day). He was encouraged to sit outside, to get dressed and to go for short walks. The staff took good care of him and soon his mood steadily improved.

Two weeks later he was asked about his earlier request for euthanasia. He replied 'Oh, that wasn't me doctor, that was the alcohol speaking'. Two weeks later he went back to live with his friends and of his own volition, recommenced chemotherapy.

THE PERILS OF PROGNOSTICATION

'If somebody is ill, and is going to die in a short time, they should be helped to die'—so the argument runs. But

how would this work in law? The timing of a patient's death is notoriously difficult to predict—all of us will have vivid memories of the times when our own prognoses have been wrong. And it is not only the timing of death that is difficult to assess. On occasion the diagnosis of a terminal illness may itself be hard to make. The *British Medical Journal* published an article entitled '“Patients with terminal cancer” who have neither terminal illness nor cancer’.⁹ The title speaks for itself. We all have our own stories in this area. Here are just two. The first comes from a well-known specialist in palliative care and illustrates the problem of ‘when is terminal, terminal?’

In January 1989, Mr. F. C. was seen as an outpatient at his local hospice. His general practitioner considered him terminally ill. The nurse attending him in the Outpatient Clinic described him as ‘all grot and crumble’.

Mr. F. C. had been diagnosed as having carcinoma of the prostate in late 1984 aged 68. Radical radiotherapy had been given in early 1985 but in January 1986 the patient had complained of bone pains and a bone scan demonstrated multiple metastases. He was treated by bilateral orchidectomy.

The metastatic disease worsened and in August 1986 he began hormone therapy. Local palliative radiotherapy was necessary on two occasions over the next two years. From then on, he continued to have a variable amount of pain. It was at the end of this period that he was referred to the hospice.

Because of the patient's wishes, examination was extremely limited and an X-ray of the pelvis and right femur could not be obtained. However, the failed hormone therapy, started nearly two and a half years before, was stopped and analgesic medicine was modified.

Three days later the pain worsened markedly and when subsequently admitted an X-ray confirmed the presence of an inter-trochanteric fracture of the right femur. He was transferred to the accident service and a dynamic hip screw was inserted.

He went home after about two weeks and gradually improved over the next few months. Three months later in May 1990 he developed symptomatic anaemia. The blood film suggested that this was related to blood loss. He was prescribed iron supplements and the dose of flurbiprofen reduced.

As he did not improve he received a blood transfusion in June 1990. Subsequent blood films suggested cancerous infiltration of bone marrow. He received further transfusions every 10–12 weeks. Eventually he developed a fulminating infection and died within hours—nearly three years after he was considered to be ‘terminally ill’ by his general practitioner.

The second example we have included comes from the study from St. Joseph's Hospice, ‘Control of distressing symptoms in the dying patient’.¹⁰ In the notes to a table describing admissions for 1982 to 1983, the following comment was made:

Note 1: ‘Not included in above are 14 patients who proved to have either no cancer at all or who had cancer in such an early stage that it was amenable to treatment. Some of these patients could not be discharged for social reasons and have become our long stay patients.’

Note 2: ‘The procedure for admitting a patient to St. Joseph's Hospice is for the attending Doctor whether in Hospital or General Practice to refer details of the patient's condition to the Emergency Bed Service. The only criterion for admission is that the patient be in the terminal stage of cancer.’

This clearly shows that patients had been admitted to the hospice, having been wrongly diagnosed as ‘terminally ill’.

GOOD INTENTIONS DO NOT MAKE GOOD LAWS

We are frequently reminded that the intentions of those involved in drawing up legislation to permit the killing of certain patients are good and honourable. But it is wholly unrealistic to assess the outcome of legislation in terms of the intentions of the legislators. We need to look carefully at the opportunities for use and abuse that such laws present: that involves looking at the likely conditions under which the law would operate. Those who support the legalisation of voluntary euthanasia stress the following guidelines:

- a) that the patient's request is free and has proved to be persistent/durable
- b) that the suffering of the patient is intractable.

In The Netherlands, where voluntary euthanasia is practised, these safeguards were also given a central position in the arguments for euthanasia. However, the extent to which they are applied in practice is open to grave doubt. For example, one survey showed that the interval between the first request for euthanasia and its performance was no more than a day in 13% of cases, no more than a week in a further 35% and no more than a fortnight in another 17%; and that in 22% of cases there was only a single request.

Further, the Government Committee on euthanasia which reported in September 1991, found that in 1990 some 1000 patients were killed without an explicit request from the patient and that over 70% of euthanasia cases were illegally reported as deaths by natural causes.

As even a leading Dutch health lawyer and supporter of legalised euthanasia has observed, there is an ‘almost total lack of control on the administration of euthanasia’ in Holland.⁶

A DOCTOR'S TRUST?

Other concerns about the legalisation of voluntary euthanasia relate to the effect such a dramatic change would have on the relationship of trust between doctor and patient. Healthcare professionals have a commitment

to care for the patient and to heal where possible. Any involvement in the intentional killing of patients would undermine the unambiguous character of this commitment in the doctor. On the side of the patient, trust in the doctor's intentions is essential to a relationship in which the patient is necessarily vulnerable. We believe that this essential trust would be eroded if patients knew that doctors were prepared to see killing as a solution to certain medical or social problems.

'Jeremy Warburg, author and publisher, died in June 1986 aged 58. For the previous six months he had kept a detailed diary of events, of his thoughts and feelings. For much of this time he was paraplegic and troubled by severe back pain. *A Voice at Twilight* is a disturbingly honest book with no holds barred. At the outset, tempers are lost. "After years of hardly a cross word we quarrel; harsh, unpleasing, unloving things are said by both of us. The cancer is threatening to tear us apart." But later, towards the end, the crucified relationship becomes alive again, at a deeper more straightforward level. The attitudes and actions of the various nurses, doctors and physiotherapists are all described. Although they are often commendable there is clearly room for improvement—"Hello Mr. W. how are we today?" is clearly patronising and a form of speech best avoided. However the telling point comes when the author perhaps inevitably reflects on suicide and euthanasia. "Strange, really. Only last year I read *Exit's Guide to Self Deliverance*—approved of it. Obvious, isn't it? Finish now, with dignity . . . Save me the agony . . . Don't want to. Astonishingly, I don't want to take or lose my life. Glad there is no euthanasia bill through Parliament. If there were, I would be even more suspicious of the people who look after me. I would think each pill designed to kill me . . . each nursing act carried out to shorten life." '11

CONSCIENTIOUS OBJECTION

Finally, legislation which aimed at providing conscientious objection would not provide adequate protection for healthcare professionals under any new law. The legalisation of euthanasia would be likely to drive conscientious objectors to it out of those specialities devoted to the care of the elderly, the debilitated, the demented and the dying.

THE WAY AHEAD

We have faced the compelling and sad stories put before us by supporters of euthanasia. We do not believe, however, that they are sufficient reason to legislate in favour of euthanasia. As healthcare professionals, we deplore the treatment that some patients have received and the pathetic social conditions which so often lie behind a request to die. However we believe that many of the stories reveal incidents of bad medicine and poor care. Bad medicine has caused trauma and torment and no doubt in some cases continues to do so in Britain today. The answer to bad medicine is good medicine. It

seems that the time has come to re-assert what good medicine is about: *cure* where possible of those who are suffering from physical and mental illnesses, and *care* of the vulnerable

To cure and care—not to kill. Part of our effort must go towards extending good models of palliative care throughout the country. No one need die in uncontrolled pain—yet sadly some still do. We must seek to ensure that knowledge of pain relief and care for the dying spreads from the hospice movements into all hospitals, GPs' surgeries and organisations which care for the sick and dying.

And our position has implications for society and government too. We have examined the reasons for euthanasia and recognise that social conditions such as poverty, bad housing, loneliness and family pressures (both emotional and financial) all play a significant role. There is much government could do to alleviate the situation. Taking serious consideration of the role that 'carers' now play in supporting many sick and elderly people and providing proper financial and social support for them would be a significant beginning. Of course the alternatives to euthanasia do cost more—emotionally and financially. But can we afford not to pursue them?

The art of good medicine includes making a good death. Not a death which involves the doctor killing his or her patient, but rather a death which involves the doctor recognising when the end has come and being sufficiently sensitive to know 'enough is enough'. Good medical practise has shown that there is much we can do to improve our care for the dying. Good medical practice is the way ahead.

The Medical Ethics Committee of HOPE gratefully acknowledges the contributions of many doctors, nurses and ethicists to this discussion, and is particularly grateful to Jane Hastings for writing up the conclusions. Available in booklet form, price £2, from HOPE, 58 Hanover Gardens, London SE11 5TN.

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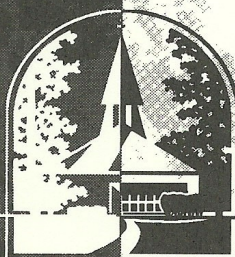
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