The Assisted Dying for the Terminally III Bill, 2004

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Background

In 1998, the Royal College of Physicians (RCP) and the Royal College of General Practioners (RCGP) established a joint working group on euthanasia chaired by Sir Stephen Tumin. The resulting position statement, which was approved by the RCP council but not by the RCGP,1 concluded that there was no reason for abandoning the profession's established view that acts motivated by a clear intention to end a patient's life could not be justified on ethical grounds. In particular, the working group rejected any change in the law on assisted suicide. However, it was accepted that 'there is a wider professional and lay view on this topic that requires continuing review'. The requirement for such a review came earlier than perhaps the RCP might have expected when, in 2003, the internationally respected human rights lawyer, Lord Joffe, introduced a Bill which, if enacted, would legalise assisted dying. The Bill is currently being considered by a Select Committee of the House of Lords and the RCP was invited to give both written and oral evidence. Written evidence was submitted in September 2004 and the authors of this paper gave oral evidence in October 2004. ²

Over the last 18 months or so, the RCP Committee on Ethical Issues in Medicine and the RCP Council has been considering this Bill. It has appeared in two versions: the Patient (Assisted Dying) Bill of 2003 and the Assisted Dying for the Terminally Ill Bill of 2004. The first version was unanimously opposed by both the Committee and by Council. The second version of the Bill, which has taken account of criticisms from many quarters, including some observations made by the Ethics Committee, evoked a more divided response.

While there has been extensive discussion of the two versions of the Bill in both the Committee and Council, there has been little opportunity to engage the College fellowship as a whole. The purpose of this article is to promote this wider debate. It is timely because, whatever the recommendations of the Select Committee, the outcome will almost certainly be a further Bill, modified in the light of the recommendations of the Select Committee, which will be brought before Parliament in due course.

The Bill

In its present version, Lord Joffe's Bill, the Assisted Dying for the Terminally Ill Bill,³ will:

enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from a terminal illness to receive pain relief medication.

The second half of this Bill, which simply reaffirms a patient's right to what most physicians would regard as ordinary, adequate care, will seem unexceptionable, even unnecessary. It is, however, intended to pre-empt the concern that assisted dying should be advocated as an alternative to competent management of one of the symptoms that might prompt the request for it. The focus of attention, however, has been on the first part, which envisages:

the attending physician, at the patient's request, either providing the patient with the means to end the patient's life or if the patient is unable to do so, ending the patient's life.

The Bill, which occupies some six and a half pages, and has 17 sections, sets out the conditions under which a request for assisted dying may be made, considered, and granted. Extensive responsibilities are invested in the 'attending physician' – 'the physician who has primary responsibility for the care of the patient and the treatment of the patient's illness'. He or she has to determine that the patient is competent and able to make an informed decision based upon an accurate understanding of:

- the medical diagnosis and prognosis
- the process of being assisted to die
- the alternatives, 'including, but not limited to, palliative care in a hospice'.

The attending physician must make sure that the patient really does have a terminal illness and that he or she is suffering unbearably, refer the patient to a consulting physician who will have to satisfy himself or herself on all these matters, and ensure that the patient has been seen by a specialist in palliative care. If there is any question in the mind of either the attending or the consulting physician that the patient may be suffering from 'a psychiatric or psychological

disorder causing impaired judgement', then a psychiatric opinion must be sought and assisted dying withheld.

A patient who wishes to be assisted to die must make a declaration on a special form included in the Bill. The declaration must be witnessed by two individuals, one of them a practising solicitor, who have to be satisfied as to the patient's identity and that he or she is of sound mind and has made the declaration voluntarily and understands its significance. Neither witness may be a member of the medical team looking after the patient, the consulting physician, or the psychiatrist, or a relative or partner. There has to be a waiting period of at least 14 days between the date on which the patient first informs the attending physician of his or her wish for assistance in dying and the date on which the patient is assisted to die. The declaration is valid for six months, after which it will lapse. It may be revoked by the patient - either orally or in any other manner without regard to his or her physical or mental state - at any time. Before actually assisting the patient to die, the attending physician is required to inform the patient of the right of revocation, check that the patient has not exercised that right, and inform him or her whether he or she would wish to do so.

These are the broad elements of the Bill. There is much more than there is space for in this article. One other clause, however, warrants attention: namely that, 'no physician shall be under any duty, whether by contract or by any statutory or other legal requirement, to participate in any diagnosis, treatment or other action authorised by this Act to which he has a conscientious objection. The precise duties of physicians who conscientiously object to assisted dying are currently being modified and the requirement (as the Bill presently expresses it) to 'take appropriate steps to ensure that the patient is referred without delay to a consulting physician who does not have such a conscientious objection' may be dropped.

The present public stance of the College with respect to the Bill

Throughout our extensive discussions, there has been much sympathy for the considerations motivating the Bill:

- a humane concern for the suffering of patients, which may in some instances be unbearable, untreatable and, given the expected outcome, pointless
- respect for a patient's autonomy as the cornerstone of medical care
- the need to protect doctors who may be uncertain of their duties in an unclear legal situation or who may be driven, by their wish to serve what they perceive to be the best interests of their patients, to actions that are currently illegal.

Nevertheless, as already noted, there is no uniformity of opinion within the RCP Committee on Ethical Issues in Medicine on the desirability of the Bill, even in its amended form, or more specifically, the ethical case for it.

For this reason, both the written and the oral submission to the House of Lords Select Committee emphasised the neutral stance of the College with respect to the desirability of the Bill (in particular from an ethical point of view), arguing that it was a matter for *society as a whole*. The particular contribution of the medical profession, as represented by the College, was to draw attention to the practical and clinical issues that would have to be addressed if the Bill were enacted and patients and the profession were to be safeguarded. In brief, we drew attention to the following:

- the accuracy of the diagnosis of the, often very complex, reasons for the request for assisted dying
- the need for specific training of those individuals who might be involved in assisted dying
- the practicalities of assisted dying
- the need for audit and documentation of the actual use of the legislation if the Bill is made law
- the parallel development of palliative care services.

Each of these proves to be more complex than it might seem at first sight. Diagnosis, for example, goes beyond simply determining the nature of the patient's illness and the physical cause of the symptoms from which she or he is seeking relief. Wellfounded confidence in the nature of the underlying disease and the specific cause of the symptoms is necessary but not sufficient. It must be clear that the symptoms cannot be resolved by any other means. Depressive illness must be identified and treated. Fears about the actual process of dying, which may be unfounded, must be elicited and discussed and allayed where possible, since this may alleviate the patient's suffering and may obviate the need for assisted dying. Unresolved psychosocial issues must also have been identified, as they may be resolved through discussion. Finally, and most importantly, clinicians should be alert to the possibility that the request for hastening death may be in response to real or perceived, explicit or implicit, external pressures, which may be internalised as the desire not to be a burden to others.

We hope that the present article will stimulate discussion in all of these areas. In addition, however, it would be appropriate to open the discussion about the fundamental desirability of the Bill. To start the debate, therefore, we would like to set out some of the arguments, for and against the Bill, that have been aired in the Committee. One of us (RT) who is in favour of the Bill has formulated a 'pro' case and the other (JS), who is against the Bill, an 'anti' case.

THE CASE IN FAVOUR OF THE BILL

There are two components to this case: what might be described as the 'primary rationale' for the Bill; and secondly, a response to concerns that have been raised about the potential adverse impact of the Bill on patients, on the medical profession and on society as a whole.

The primary case: is the Bill necessary or desirable?

The clinical need for assisted dying

A 1994 survey of UK doctors⁴ found that 12% had admitted to taking active steps to end a patient's life. In another study, in 1996, 12% of doctors knew a colleague who had assisted a patient to die, 4% claimed they had provided a patient with the means to end their life, and 28% had been asked to provide the means for a patient to end their own life.⁵ A survey of 2,000 doctors in *Doctor* magazine (1995) found that 62% had been asked by a patient to hasten their death.⁶ A survey by the *Sunday Times* in 1998 found that one in seven UK GPs admitted to helping a patient to die at their request.⁷ Nurses are also being asked by patients for their help to die.⁸

It has often been argued that this simply reflects the unavailability of good palliative care and that, if this were universally available, there would be no need for assisted dying. This is not the case. The limitations of palliative care in some patients have been recognised by the National Council for Hospice and Specialist Palliative Care Services, the British Medical Association and Macmillan Cancer Relief. For example the National Council for Hospice and Specialist Palliative Care states on its website (August 2004):

universal availability of excellent palliative care services will not and can never eliminate all such rational and persistent requests for euthanasia ... we acknowledge that maintaining a legal prohibition on the practice of euthanasia exacts a high price on some individuals who may feel that their autonomy has been unacceptably compromised.¹⁰

This observation about the limitations of even the best hospice care is reinforced by the experience in Oregon where the Death with Dignity Act has been in place since 1997. All Oregonians have access to hospice care; nevertheless there are still patients who seek assisted dying through the Death with Dignity Act. Indeed, in 2003 93% of patients using the Death with Dignity Act were in hospice care.¹¹

One consequence of the current situation is that many patients either attempt suicide and botch it, or seek help from friends and relatives, or even in some cases go abroad, for example to Switzerland where assisted suicide is legal. Everyone will be familiar with the tragic case of Diane Pretty who was dying from motor neurone disease.

Is there a need to change the law?

Many clinicians are understandably anxious about bringing more aspects of clinical practice within the ambit of statutory law, preferring informal arrangements. This thinking is entirely out-of-date, misguided and potentially puts both clinicians and patients at risk.

Currently, assisting a suicide, even if the patient is terminally ill, could expose the doctor to a term of imprisonment of 14 years. Helping a patient to die directly would render the doctor liable for life imprisonment on the grounds of murder. With increasingly close scrutiny of doctors, and a vocal minority of individuals who feel doctors ought not to be trusted to make ethical decisions, even humane care is becoming more difficult, with increasing suspicion regarding the use of morphine and insistence on cardiopulmonary resuscitation, often in totally inappropriate circumstances. Furthermore, there is a desire for a change in the law amongst the public which has remained consistently in favour of assisted dying at over 80% since the mid 1990s. Most importantly, this percentage shows negligible variation with either the age or the social class of the respondents. In

Finally, it is of interest to note that three of the House of Lords Select Committee members who were unable to support assisted dying in 1994 now support the Joffe Bill (Baroness Flather, Baroness Warnock and Baroness Jay).

The central ethical case

Some people will be opposed to assisted dying on religious grounds, although it is interesting to note that there is widespread support for it among religious groups. ¹⁴ Of wider concern is the question of whether assisted dying would be compatible with the fundamental principles of biomedical ethics.

The key principle here is that of 'respect for the autonomy of the patient'. This is central to medical practice. To deny this at the end of an individual's life, when they are in what they deem to be a state of unbearable suffering for which medicine can offer only inadequate palliation, would seem to be a gross violation of the notion of medical practice rooted in respecting a patient's wishes. Even those who would deny autonomy as the sovereign principle of biomedical ethics, would find it difficult to oppose assisted dying on the grounds of the other fundamental principles – such as justice, non-maleficence or beneficence.

In most cases, the hostility to assisted dying has arisen out of the concern not for the individual patient but for other patients. This concern (as we shall discuss presently) is ill founded. However, in itself, it is unacceptable as an overriding consideration. As John Harris has pointed out:¹⁵

respect for persons ... requires us ... to treat them as ends in themselves not merely instrumentally.

We do not determine the medical treatment of patients on the basis of what would be best for *other* people. Harris quotes Ronald Dworkin's memorable observation that:

making someone die in a way others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny.¹⁶

Denying patients assisted dying when the best possible palliative care has failed to address unbearable symptoms is, effectively, abandoning them, as has been pointed out by the palliative care physician, Timothy Quill.¹⁷

The secondary case: would the Bill, if enacted, have potentially adverse effects?

Risk to individual patients

There are four areas of concern here:

- capacity and competence to make a decision
- diagnosis
- the 'pressure to die'
- the availability of palliative care.

Capacity: Doubts about the capacity of a patient to make a decision in this context, while understandable, are inconsistent with the basic presumption of capacity recently affirmed as the foundation of law in medical decision-making (Dame Butler Schloss, Miss B decision 2002). There are, of course, many safeguards included in the Bill to protect patients who lack the capacity to understand the significance of their request for assistance to die.

Diagnosis: It is self-evident that depression and other treatable conditions should have been identified and treated. The Bill has safeguards to minimise the chance of misdiagnosis, which anyway will be least likely in the case of a patient at a terminal stage of a progressive illness. (Medicine, however, often requires decisions, which may have grave consequences for patients that fall short of 100% certainty.) It is recognised that patients sometimes change their minds, often when psychosocial issues are resolved, and this is catered for in the Bill which requires a minimum of 14 days between the patient making a formal request for assisted dying and that request being confirmed prior to implementation. In many cases the period of time may be much longer. What is more, evidence from Oregon suggests that the knowledge that assisted dying is available may be sufficient in itself to resolve some symptoms.¹¹ Only 60% of people who get a prescription actually use it. It is as if it is a kind of insurance.

External pressures: There is a concern that the patient may simply be passively transmitting external pressures from others who have reasons to wish they should die, or internalising the views of others as a sense of worthlessness. This, of course, should be identified by the attending or consulting physician, or the palliative care team.

Availability of palliative care: Finally, there is a concern that patients may be denied palliative care if the assisted dying option is available. The present Bill anticipates this and insists that the palliative care filter should be passed through first (see also below).

Wider impact on care

It has been suggested that the availability of assisted dying would remove pressures to improve services for terminally ill patients. In fact, evidence from other countries, where assisted dying is available shows the opposite effect: the safeguards around such bills have mandated the improvement and rapid development of palliative care services. ¹⁸ It is of note that Oregon has been identified as the second best state within the USA for dying or end-of-life care. Investment in palliative care services has increased enormously in the Netherlands since assisted dying was available. ¹⁹

Impact on the profession

While assisted dying may not require a physician, it is probably preferable that the patient should be supported by physicians who have cared for them prior to the final stages. Assisted dying should be seen as part of the overall 'therapeutic alliance' in which patients will know that doctors will be with them to the end, providing them with whatever they need to produce the outcome that is best for them. Some have, therefore, worried that the relationship between doctors and society may alter if they were involved in assisted dying. There is no evidence from experience in other countries that this would diminish trust in the medical profession; indeed, information from the Netherlands and elsewhere has suggested doctors are held in higher regard than in other European countries where assisted dying is not legalised.²⁰ A recent study has shown that the availability of assisted dying has improved communication between doctors, patients and families concerning end-of-life decisions.²¹

At present, doctors in the UK are increasingly aware of an atmosphere of free-floating distrust that makes even humane end-of-life care quite difficult. The closer scrutiny to which physicians will be exposed as a result of the Assisted Dying Bill will be reassuring for everyone, including physicians themselves who, as already noted, have sometimes been in danger of prosecution for assisting patients in ways that they feel are appropriate. The fear that they may become 'case-hardened' as a result of being repeatedly involved in assisted dying seems unfounded. Onwuteaka-Philipsen et al found that, not only had there been no change in demand for physician-assisted death in the Netherlands between 1995 and 2001, but that physicians 'seem to have become more reluctant in their attitude towards this practice.²² Assisting a death will not be a common experience for the average physician. Moreover, in view of the effort it involves and the emotional calls it makes on the physician, it will be a marker of sensitivity to suffering rather than complacency about it.

Wider impact on society

Contrary to what is frequently asserted, there is no evidence from experience in the Netherlands, Belgium or Oregon that there has been a devaluing of life in countries that have physician-assisted dying legislation. Indeed, it has been argued that, with the regulation of end-of-life decision-making, there is greater care in the management of terminally ill patients. What is more, where a regulated system is lacking, non-voluntary euthanasia (doctors ending life without the request of patients) is higher than where there is provision for assisted dying.²³ There is evidence from the Dutch experience that the proportion of deaths due to 'life-ending acts without explicit request' is lower than in countries where assisted dying has *not* been decriminalised.²⁴ The 'slippery slope' notion that assisted dying would be imposed upon the vulnerable is not supported by evidence from Oregon, where those who have assisted dying are more educated, have a higher socio-economic status and are not motivated by poor social support.²⁵

THE CASE AGAINST THE BILL

Introduction: the Bill and the responsibility of physicians

Public policy results from an ethical decision on morally relevant facts. Sometimes those facts are so clear, and the principles behind the ethical judgement so widely accepted, that medical institutions may become strong advocates of public policy or legislation. Smoking and health is an example. On other occasions, the evaluation of the facts is more difficult, the facts themselves disputed and the principles less clear. End-of-life issues raise questions of values at the most basic level. Doctors at the bedside have experience of the dying patient. More than most, they have an intimate understanding of the morally relevant facts that are the substrate of debates over assisted suicide and euthanasia. Reflective physicians, therefore, have a responsibility to be informed and to inform public debate. So do medical institutions as they attempt to express the collective wisdom of their members.

This Bill aims to legalise certain categories of killing: killing of the patient by himself with medical assistance if possible, killing of the patient by the doctor if not. It is not a Bill about assisting dying but about assisting death. Giving barbiturates followed by curarisation is not assisting dying: it intentionally causes death.

Is the Bill necessary?

More patients die in hospitals, than in hospices or at home; most do not die from cancer or motor neurone disease; and most are not offered specialist palliative care. We do not know how often the *best* palliative care fails. We know care can fail because pain control is poor,²⁶ nausea underestimated, breathlessness badly managed or dignity-conserving care poor.

Desire for death may then be associated with unnecessarily poor symptom control, loss of social connectedness, hopelessness, associated depression, or 'feeling a burden'. This is not an argument for killing the patient: it is an argument for better terminal care.

Under this Bill, the prognosis of that terminal illness (whose

definition could encompass emphysema, chronic degenerative disorders, complicated diabetes) may be 'months'. Given the inaccuracy of prognostication, let alone the current evidence on end-of-life decisions, which are largely in the last four weeks of life,²¹ this is indefensible. Casual asides about the probabilistic nature of medicine are not an adequate riposte.

Suffering is multifactorial, often with deep personal and social dimensions. Full assessment may take weeks, as relationships of trust about intimate concerns are developed. Patients do change their minds.²⁷ The Bill's proposed single assessment by the 'independent' 'consulting physician' is tokenism, not effective gate keeping. It could last a few minutes, and 'independence' is undefined. Probably, the second opinion will always be asked of the same person, who will rarely differ from the first. The destabilising effects of terminal symptoms upon competence are not even addressed.

Is the Bill morally justifiable?

The moral argument for patient-assisted suicide and active voluntary euthanasia (PASVE) is based on autonomy. Autonomy is more than atomistic individualism. Euthanasia is not another consumer product to demand from the supermarket of life. We are born dependent on others and we die dependent on others. Our dependence is as much a characteristic of what it is to be a person as is our capacity to make free choices.

Firstly, autonomy in a society in which the commitment to support ailing human life has been modified differs significantly from autonomy in a society with differing values. It is the prevailing social ethos which informs what seems to be 'rational' to any individual and upon which an 'autonomous' decision is made. There are, especially, concerns about vulnerable groups being considered less worthy of living and seeing themselves as such.²⁸ A humane social ethos is not an abstraction: it is the cultural air we breathe. This is easily taken for granted. If we lived under the Taliban or any number of modern states whose citizens seek asylum in the West, it might not seem so abstract. We do not need to conjure up Nazi fantasies to acknowledge that the veneer of civilisation is thin. Economic pressures, worship of youth and health, frustration at medical impotence and the desire to lift the burdens of caring easily lead to impatience with the weak, the old, the handicapped and the dying.

Secondly, if the moral case for euthanasia rests upon autonomy, there is no reason for its restriction to those with a prognosis of a few months. If there are non-terminal patients – or those with no physical ailment – who consider their lives no longer worth living, then, as autonomous agents, there can be no reason to withhold the 'benefit' of death from them. Alternatively, if we think that eligibility should be restricted – as the current Bill does – we imply that autonomy is not the sole or supreme consideration. If autonomy should be exercised only when someone's life deteriorates beyond a certain point, we implicitly assert that at some point it is trumped by a societal commitment to support hindered and afflicted human individuals in living as well as possible. In that case, we must explain where we draw the line and give strong reasons for drawing it

there rather than elsewhere. Why at 'a few months' prognosis? The need for strong reasons is that in their absence it will be difficult to maintain the restriction. Once we concede that physicians may kill their patients upon request – or help them kill themselves – strong reasons for restricting eligibility are hard to come by.

Thirdly, the fact that one's life is one's own is not an argument for saying that one has a moral right to choose to end it. Even with property, it might be morally wrong to destroy what one has a legal right to destroy (suppose you owned a Rembrandt?) Given that humans have social obligations, autonomy must be exercised in a context of human obligations, rather than an exclusive one of individual good. In practice, we do override individual preferences in all sorts of situations: most obviously in having laws at all. And we do send people to their painful deaths in (we hope) just wars or hazardous occupations, for example, for social good. So it is not at all obvious that autonomy dictates a right to be killed. The social ethos required for human flourishing is not compatible with unfettered choice. As an extreme example, in the Meiwes case²⁹ consensual (autonomously chosen) self-mutilation and cannibalism was not only judged illegal but considered immoral by most commentators. Some suffering may be justified in defence of a valuable social ethos that protects the well being and flourishing of us all. A humane society cannot be laissez faire in its regard for the treatment of the lives of human persons. Since the change to the social ethos is long term and difficult to assess, the extent of intractable and unmanageable terminal suffering needs urgent assessment before legislating for killing. Experience from recent legislation in Belgium (2002) and the Netherlands (2001) does not help us.

A moral case cannot be determined by opinion polls. Democratic legitimation is ethically unreliable.³⁰ Many assertions rest on dubious questions in methodologically flawed polls. Treatment withdrawal and possible effects of opioids confuse responses. Nevertheless, it is striking that those most closely involved with dying patients – nurses and specialists in palliative care – have failed to support this Bill.^{2, 31}

Would the Bill regulate current practices?

Proponents of the Bill are keen to assert that it would bring the practice of covert euthanasia into the open, where it can be audited and assessed. Experience from the Netherlands suggests that about half the cases of 'euthanasia' and 'assisted suicide' revealed by the 2001 survey went unreported, as did 99% of cases of termination of life without the patient's request, 100% of cases of intentional overdose of patients (whether requested or unrequested), and a huge majority of cases where the patient was a child.³² It is, in any case, a strange logic to argue that because doctors may currently break the law, therefore the law should be changed. No doubt, doctors break the speed limit or fiddle their tax returns too.

Would the Bill damage the profession?

Doctors in the UK have been subjected to intense media criticism: events such as those of Alder Hey, Bristol and Shipman have led to distorted and negative press coverage.³³ Remarkably, doctors are still trusted by most people. Whatever the short-term international experience, there are legitimate anxieties about the effects of this Bill on doctor-patient relationships, which, by international standards, are already increasingly open and based on mutual dialogue.

Pressure for further extension of euthanasia is an inevitable consequence of the Bill, for which there is already ample evidence. Unregulated activity of a wider sort would be the result.^{34,35}

With perhaps 0.5–3%²⁶ of deaths produced by PASVE, involvement will be a relatively common experience for some doctors. Yet, it has not been determined how patients will access their legal rights if their own physician has conscientious objection. Amendment of the Bill is awaited as it is in probable conflict with the European Convention on Human Rights, highlighting yet another deficiency in the proposal.

In summary, this Bill addresses a problem that is probably small in scale. Its proposals create serious problems of both principle and practice, and could foster grave social evils. There is an alternative: improved palliative care, extending *in extremis* to sedation that is ordered to relieve suffering and not to kill, but which may nevertheless risk death, but without intending it.

Dignity has been called a 'linguistic currency that will buy a basketful of extraordinary meanings'. Nevertheless, respect for a patient's life is part of respect for that patient's human dignity. The law should continue to uphold that dignity by maintaining its prohibition on homicide or assisted suicide. Suicidal people should not be confirmed in their own estimate of their lives' value: instead they should be supported and protected, whatever their physical condition.

WHERE DO WE GO FROM HERE?

This, then, is the current state of the debate within the Royal College of Physicians: agreement as to the specific role of the medical profession in ensuring that, if the Bill were enacted, patients (and clinicians) would be safeguarded; and disagreement as to the desirability, or even the necessity, for the Bill in the first place.

We hope, therefore that this article will stimulate a wider debate on both the ethical and clinical issues for this is an issue that will not go away and will need to be addressed.

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