# llora G Finlay

# Assisting suicide is no therapy

#### Summary

It is a paradox that, as medicine has begun to deal with the symptomatic problems of terminal illness, demands for legalised euthanasia have become more strident. This paradox is explained by recognising that the driving force of present-day demands for legalisation is the growth in society of individualism and an increased emphasis on notions of autonomy and personal control. Recent proposals for legalisation in the UK do not pass the 'real world' test of clinical practice and terminal suffering, and their so-called safeguards are paper-thin. Whether one can accept the principle of legalised assisted suicide/euthanasia depends essentially on one's personal or social values, but the case against medicalised euthanasia is particularly strong. Euthanasia as part of the health care system — and thereby a therapeutic option — conflicts with good medicine, and introduces a quasi-commercial customer-supplier relationship into doctor-patient relationships. Because it seeks to set euthanasia/assisted suicide within the comfort zone of health care, it disguises its real nature and thereby exposes vulnerable patients to greater risk.

**Key words:** euthanasia, assisted suicide, autonomy, palliative care, reality, vulnerability, health care, choice, doctor-patient relationships, clinical practice

# The development of palliative care in the UK

When I qualified as a doctor 36 years ago, palliative care was in its infancy. It was only a few years since Cicely Saunders had opened the first hospice in the UK and begun her pioneering work to treat 'total pain' – body, mind and soul. There was, by today's standards, little that could be done to remove the physical pain and discomfort and to ease the stresses and anxieties of patients who were terminally ill. Yet there was little pressure to change the law in Britain to legalise euthanasia<sup>1</sup>.

Contrast this with the situation today. Palliative care has come of age. For the last 21 years in Britain it has been a recognised clinical speciality, with lengthy and demanding training for those wishing to qualify. In addition to voluntary sector hospices and community teams, there are now specialist palliative care services in most major hospitals. There are still some instances



Ilora G Finlay FRCP, FRCGP is Professor of Palliative Medicine at Cardiff University, UK, and Independent Member of the House of Lords. Email finlayi@parliament.uk

of 'bad deaths', often because the distribution of specialist palliative care has not kept pace with the rapid advances that have been made in its quality, but they are rarer than they were.

At the same time the public have rightly realised that dying is not synonymous with pain and overwhelming distress and they no longer accept bad care. This pressure has resulted in the British Government committing more resources to palliative and other end-of-life care in order to correct the deficiency.

## A modern paradox

Yet, paradoxically, at the same time as we have seen these advances in palliative care we have also witnessed an increasingly strident demand for the legalisation of euthanasia and/or physician-assisted suicide. In the last five years there have been three such bills introduced into the House of Lords, the Upper Chamber of the UK Parliament. The first was withdrawn after it failed to secure sufficient support in its early stages; the second was referred for examination to a select committee, which failed to reach agreement; the third was put to a vote and roundly defeated.

Notwithstanding these clear signs that Parliament has little appetite for changing the law to allow what is being euphemistically called 'assisted dying' or' 'assisted death', the main pressure group – which re-branded itself two years ago from the 'Voluntary Euthanasia Society' to 'Dignity in Dying' – is obviously gearing up for another attempt.

#### The ideology of autonomy

Why, it may be asked, should there be increasing demands to legalise euthanasia at precisely the same time as palliative care is beginning to deal with the problems of terminal illness? The key to this riddle is to recognise that the main driving force behind these demands for 'assisted dying' is no longer a concern that people are frequently dying in pain or with overwhelming suffering. The demand for legalised 'assisted dying' is yet another manifestation of a phenomenon which has become widespread in the Western world over the last two or three decades – namely, a trend towards individualism and personal control of life.

Four years ago I spent six months as a member of the House of Lords select committee, which examined the second 'assisted dying' bill to be presented to Parliament. This bill, if it had become law, would have allowed either physician-assisted suicide or physician-administered euthanasia for terminally ill, mentally competent adults who had been given a prognosis of six months or less. The bill's sponsor, Lord Joffe, told the select committee that his bill was "based on the principle of personal autonomy and patient choice, the right of each individual to decide for themselves how best he or she should lead their lives"<sup>2</sup>. Another witness to the inquiry, who was supporting the legalisation of euthanasia, told us that "it is only by the exercise of autonomy that our lives become in any real sense our own"<sup>3</sup>.

Statements like this would have caused eyebrows to be raised 30 or 40 years ago. The notion that each one of us has a right to decide exactly how we should live may sound libertarian, but a moment's thought shows it to be unsound: it takes no account of the impact of individual actions on other people. The idea that those who are not in a position to exercise autonomy do not have real lives sounds like a philosophy designed only for healthy and wealthy people living in democratic societies. It also fails to recognise that a central role of palliative care is to ensure that patients have real choices about every aspect of their care, including where they wish to be, and have support to experience quality to their lives.

When someone feels hopeless and helpless, death may seem the obvious solution to their problems, but so often hope is restored by careful attention to the values of the individual, restoring their sense of personal worth, and by helping them find ways to achieve unfinished goals.

#### We don't live in a perfect world

The three attempts to legalise 'assisted dying' in the UK all share another fundamental characteristic. They assume the existence of a perfect world – a world in which all doctors know their patients well enough to understand their underlying fears and anxieties and to assess whether a request for euthanasia stems from firm conviction or simply a sense of hopelessness or obligation to others, a world in which all terminally ill people know their own minds clearly and always act rationally and understand the real implications of the choice they are being offered. Anyone who works, day in and day out, among dying people knows that this idealised picture is simply not an accurate representation of what really happens.

In the real world most people who receive a terminal prognosis are frightened – whether it is fear of pain, of becoming immobilised, of incontinence, of becoming dependent on others, or just of dving itself. Very few of them are able to say, calmly and without hesitation, that they accept their situation and want help to end their lives. The pro-euthanasia lobby, of course, concurs with this view and goes on to argue that, for this reason, there would not be many actual cases of euthanasia if the law were to be changed. But, again, this simply doesn't pass the 'real-world' test. It assumes that terminally ill people are either fully resolved that they want to end their lives or firmly opposed to such a course. In reality the vast majority of people facing dying are ambivalent, oscillating between hopelessness and hope, worrying about being a personal or financial burden on those they love or that their own care costs will erode their descendants' inheritance. In a word, they are vulnerable, and it is a primary purpose of any law to protect the weak and vulnerable rather than to give 'rights' to the strong and determined at their expense.

#### How safe are the so-called 'safeguards'?

Advocates of euthanasia respond to this with the assurance that any 'assisted dying' law would come with 'safeguards'. Once again, we have the idealised world of the philosopher rather than the real world of the doctor or patient. Drafting a law in the comfort of a parliamentary chamber is quite different to making it work amid the uncertainties of everyday life. Let's look at some of the safeguards and see how they measure up.

We are told that euthanasia would be restricted to patients with specific diagnoses and prognoses. But in the real world diagnostic errors abound, and predicting the course of an illness is extremely difficult and often inaccurate. According to the Royal College of Pathologists in evidence to the House of Lords select committee, post-mortem research and clinical audit studies carried out in the USA and Europe consistently show serious errors of diagnosis, including terminal illness, in about 1 in 20 cases. Another witness, from the Royal College of Physicians, told the select committee that "prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless

as an accurate factor"<sup>4</sup>. These serious uncertainties are not generally recognised by a public which mistakenly regards medicine as an exact science and which has become accustomed to shorthand phrases in the media such as 'three months to live'. The reality is very different.

Then there is the requirement that every application for euthanasia should be assessed by two doctors. While this may sound reassuring to the layman, it is far from providing a real safeguard. It is notable that in those countries which have legalised euthanasia the training of the second-opinion doctor does not require full specialist palliative care training – indeed, it is usually limited to only a few hours' tuition – nor stipulate the quality or extent of any assessment that they make.

While it may not be too difficult to identify applicants who are clearly convinced that euthanasia is the only thing they want or to spot those who are obviously being coerced, assessing the vast majority who fall between these extremes is more of an art than a science. Even when a doctor has known a patient personally for long time, assessing the effects of adjustment disorder, medication or metabolic disturbances, or even mild delirium in the intelligent and articulate can be difficult. For the second-opinion doctor who has not known the patient, disordered thinking can be almost impossible to detect.

Then there is the criterion of 'unbearable suffering'. There is no requirement that efforts should have been made to relieve such suffering before an assessment can proceed, either in the Netherlands or in Belgium. In both countries the patient only has to be informed of the option and consequences of palliative care; it is notable that in Belgium when patients actually experience specialist palliative care, the vast majority abandon their quest for euthanasia. Dutch law stipulates that the doctor must "be satisfied that the patient's suffering was unbearable" - and must "have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation". But it is difficult to see how that can be accurately assessed as suffering is such a subjective phenomenon. Unbearable suffering is often seen in those who are not terminally ill, such as those with psychiatric illness or the parents of a child who has been murdered. Indeed, in evidence to the House of Lords select committee one pro-euthanasia witness admitted that, "with all the safeguards and all the expertise being available, it is that person in the end whose view should prevail, because it is about the quality of that person's life"5. In practice, therefore, the criterion of 'unbearable suffering' offers very little protection.

#### Can euthanasia ever be justified?

So am I saying that there can never be circumstances in which euthanasia might be justified? In answering this question it is necessary to draw a distinction between two things - euthanasia as a concept and medicalised euthanasia. Whether one is able to accept the concept of euthanasia – the notion that there could be circumstances in which it would be acceptable to end, or help to end, the life of another person at his or her request - depends largely on one's personal and social values.

As a doctor, however, I am in no doubt that the case against medicalised euthanasia is overwhelming. I have two main reasons for taking this view. One is that it has a corrosive effect on clinical thinking, by removing the pressure to re-double efforts to relieve suffering and restore hope; it makes ending life seem a way out of a difficult situation for the doctor as well as for the patient. And the other reason is that this involves greater exposure of patients to danger.

#### Clinical ethics and patient choice

The impact on medicine was eloquently covered by the General Medical Council (GMC), the body charged with the regulation of clinical practice in the UK, in their evidence to the select committee:

A change in the law to allow physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients. Acting with the primary intention to hasten a patient's death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence.6

All the Medical Royal Colleges in Britain and the British Medical Association have, after consultation with their members, declared their opposition to a change in the law to permit 'assisted dying'.

These positions are hardly surprising. Doctors are trained to treat illness where they can and to relieve its symptoms where they cannot. This often involves decisions to cease interventions that are not achiev-

ing a benefit, doing everything to improve quality of life and accepting that death is a natural conclusion to life. But the brief does not include deliberately ending a patient's life, even if that is what some of their patients may say they want. Respect for patient choice is, of course, a key ingredient of good clinical practice, but it cannot override sound medicine. Choice does not mean that patients can have whatever they demand. As another witness told the select committee, if patient choice were the paramount consideration in clinical practice "I would have done many unnecessary operations and some harmful operations in my time as a surgeon"7.

The fact is that the relationship between a doctor and a patient is not the simple commercial one of a customer and a supplier. As the GMC rightly observed it involves the ethical principle of beneficence. It is important that patients, who by their very circumstances are vulnerable, should be able to trust their doctors always to act in their best interests, even if those interests are not immediately apparent to the individual patient at any given moment.

## Euthanasia as part of health care?

This brings me to the second objection to medicalised euthanasia. Advocates of euthanasia insist on presenting 'assisted dying' as an integral part of health care. Their reasons for doing so are understandable. It is widely, and rightly, assumed that a doctor will always act in his patient's best interests. It follows that a doctor's participation in 'assisted dying' confers on the act an aura of benevolence which commends it the more easily both to law-makers and to the public at large. Putting it outside the health care system exposes it for what it is.

Those who want to see the law in Britain changed argue that there are compassionate reasons for embedding euthanasia in health care and that it would be hard-hearted to expect people who are suffering greatly and who want assistance to end their lives to be deprived of the support of their doctors in doing so. But, as with all law-making, the first priority must be to ensure that the interests of the majority are not prejudiced by any rights accorded to a minority. If someone is truly serious about wanting to end his or her life, he or she will not be deterred because assisting suicide is not part of the health care system. But we are being presented with the notion of 'assisted dying' within the comfort zone of health care and as just another therapeutic option, or something that those who fear being a burden on others ought to do. Even if they should decide against it, the problem would not go away there and then. As another witness told the select committee, "some patients, while not opting for ending their lives, would feel themselves to be presented, if the law were to be changed, with an ongoing choice to be made"8.

#### Wider consequences of the British debate

The law in Britain protects the great majority of terminally people, at least as much from themselves as from other people. Dr Kathleen Foley of Memorial Sloan-Kettering Cancer Center New York, giving evidence to the select committee four years ago, drew attention to Britain's lead in specialist palliative care and its wellestablished hospice programmes. She told the select committee that legalising physician-assisted suicide in Britain would "be a very strong statement that Britain makes to the world that its way to focus on caring for the sufferer is to kill the sufferer"9. If Britain were to go down the road of legalisation, that could well jeopardise the care of terminally ill patients around the world.

#### References

- In this article the term 'euthanasia' includes what is normally referred to as voluntary euthanasia and assistance with suicide.
- House of Lords Paper 86-I (Session 2004-05), paragraph 22.
- 3 Ibid., paragraph 41.
- Ibid., paragraph 118. 4
- 5 Ibid., paragraph 129.
- House of Lords Paper 86-II (Session 2004-05), page 112.
- 7 House of Lords Paper 86-I (Session 2004-05), paragraph 45.
- 8 Ibid., paragraph 97.
- House of Lords Paper 86-II (Session 2004-05), page 593.