

# A Time to Live, A Time to Die?

**PROFESSOR ANSELM ELDERGILL** details the problems associated with the Assisted Dying Bill which has its second reading on Friday

To every thing there is a season. A time to be born, and a time to die; a time to kill, and a time to heal. So says the Old Testament.

The Terminally Ill Adults (End of Life) Bill has its second reading in Parliament on Friday. It aims to give many adults with less than six months to live the right to end their life with medical assistance at a time of their choosing.

The proposed framework is relatively simple but controversial, and in some respects flawed.

An adult is only entitled to physician-assisted suicide if their death ‘can reasonably be expected within 6 months’ because of an ‘inevitably progressive illness, disease or medical condition which cannot be reversed by treatment’.

The patient must be registered ‘as a patient with a general medical practice in England or Wales’, which suggests that the procedure may be applied in general practice settings and become quite widespread.

The adult must have capacity to decide to end their own life and have ‘a clear, settled and informed wish’ to end it. Their decision must have been made ‘voluntarily’, without pressure or coercion.

If the patient makes a statutory declaration to this effect, their ‘coordinating doctor’ must verify in a statement that these conditions for assisted suicide are satisfied. This doctor then refers the patient to a suitably trained ‘independent’ doctor who, after a 7 day ‘period of reflection’, has to confirm that the conditions are indeed satisfied.

It is then for the patient to apply to the High Court for a declaration that the court is also ‘satisfied’ the conditions for assisted suicide are met. The court’s jurisdiction is limited to this single question.

If the court is ‘satisfied’ that the conditions are met, the patient is required to confirm their request for assisted suicide in a second declaration made after a further ‘period of

reflection' of 14 days (or 48 hours if they have less than a month to live). The coordinating doctor has to confirm this.

The physician-assisted suicide may now take place. The coordinating doctor (or an authorised doctor nominated by them) may legally provide the patient with the 'approved substance' and assist them 'to ingest or otherwise self-administer' it. The doctor may not 'administer' the substance and the 'final act of doing so must be taken' by the patient.

It is not clear in what sense a doctor who assists a patient to ingest the substance is not jointly administering it or jointly undertaking the final act.

Readers will have a range of views about whether what the Bill proposes is justified. Unless one believes in a God it is not possible to say that a particular value or code of conduct is undeniably right or undeniably wrong. If there are no absolute God-ordained laws one is left only with a set of relative laws that express human values, and these vary from person to person and across time and place. It is a question of which values society should prioritise from the many competing values to be taken into account.

In this instance, it is a case of balancing an individual's right to personal autonomy — which includes their right to avoid what, in their view, may be an unworthy or painful end to life — with the duty of society and the medical profession to protect life, and in particular the lives of vulnerable citizens.

There are, however, considerable practical problems with the Bill that need to be addressed. The fact that it is being introduced as a Private Members Bill, rather than as a government Bill following a Royal Commission or Law Commission report and a period of prolonged consultation and reflection, is fraught with danger.

In the first place, the active involvement of doctors and nurses in taking the lives of patients risks changing patients' perceptions of these professions, and could undermine trust in them, particularly amongst the elderly and frail or terminally ill.

The 'six-month rule' suggests a degree of prognostic reliability that does not accord with reality. In one recent London study over ten years, doctors' predictions that their patient would survive for a period of 'months' were only accurate in 32% of cases. 37% of the patients lived for a year or more.

How long a person can reasonably be expected to live partly depends on where they live, the availability of newer treatments within the NHS or at their local NHS hospital, and access to expensive private medical treatment. There is a social class bias.

For those who advocate voluntary euthanasia, as a way of sparing individuals prolonged further suffering, it is notable that the Bill does not in fact cater for many or indeed most of the test cases that have come before the courts in recent years.

These cases usually involved people with more than 6 months to live who were severely disabled and had to endure great suffering and indignity as the result of a progressive,

untreatable neurological disorder. The well-known case of Diane Pretty, who had motor neurone disease but more than 6 months to live, is one example.

In a famous German case, a woman with total sensorimotor quadriplegia was almost completely paralysed and required artificial ventilation and constant nursing. She had a life expectancy of at least 15 years and wished to end what was, in her view, an undignified life by committing suicide with her husband's help. In the end, he transported her on a stretcher more than 700 kilometres to Zurich where she committed suicide, assisted by Dignitas.

Under the Bill, the suffering of such people must continue until it can reasonably be said they have less than 6 months to live. Conversely, people who are expected to die within 6 months may choose physician-assisted suicide, even though they are not physically suffering and their death is likely to be painless. For example, a frail, very elderly person whose body is gradually shutting down.

Indeed, strictly speaking, their wish to die now need not arise from the fact they are believed to have less than six months to live. It could simply be that they no longer derive pleasure from life.

Proponents of the Bill argue (erroneously) that there is no evidence from the experience of other countries which supports the view that the legislation may be the beginning of a 'slippery slope' that leads to physician-assisted suicide being extended to include persons not currently within the Bill's scope.

Anyone who has listened to debates on assisted suicide in recent years is likely to conclude that for some campaigners the Bill is a Trojan Horse; a wedge in the door. Once the taboo on assisted suicide and euthanasia is broken, it will not be long before they seek to extend its provisions.

From one viewpoint that ought not to be fatal for the Bill if the scheme it proposes is justified; one can simply oppose its future extension. However, the breaking of such a well-established taboo normalises the practice of doctors helping patients to die and makes it less likely that people will oppose what may then be dangerous or ill thought out extensions.

It can, I believe, confidently be predicted that campaigners would soon seek to extend assisted suicide to persons with constant and unbearable physical or mental suffering as the result of an incurable condition that cannot be appeased, as in Belgium.

Over time that is likely to be flexibly interpreted by doctors sympathetic to euthanasia or engaged in the new medical speciality of physician-assisted death. For example, in a Belgian case called Mortier, a woman with a 'severe personality disorder' who had been depressed for 40 years but had never required in-patient treatment satisfied this unbearable suffering test.

She was not alone. One study in Belgium examined the cases of 100 psychiatric out-patients requesting euthanasia because of 'psychological suffering'. 58% were

diagnosed with depression, 50% had a ‘personality disorder’ and 12% Asperger syndrome. 48 of the requests were accepted and 35 carried out.

Many people who have tried to assist individuals experiencing long-term mental ill-health will be deeply troubled by those findings. Given the role that isolation, poverty, social deprivation, social exclusion, gender and racial injustice play in mental health, they will wonder whether these out-patients were offered adequate, intensive assisted living — in the form of better housing, occupational activity, social and financial support — before being assisted to die.

The United Nations has expressed concern that, even when restricted to those with a terminal illness, ‘people with disabilities, older persons, and especially older persons with disabilities may feel subtly pressured to end their lives’ due to social attitudes and lack of appropriate services and support.

It will next be argued that the law is discriminatory, because it excludes individuals with a significant learning disability or mental illness who legally lack capacity to decide to die. Why should they suffer unnecessarily? The United Nations Convention on the Rights of Persons with Disabilities, which prohibits discrimination on the ground of disability, will be pleaded in support.

Then the fact that children are excluded will raise the objection that this too is discriminatory. Why must they endure prolonged suffering until they are 18? In Belgium, this objection has resulted in the right to euthanasia being extended to children, while in the Netherlands children aged 12 to 15 can now request euthanasia with parental consent.

There are a number of practical issues that seem not to have been fully thought through by the Bill’s drafters or are left to the Minister to decide.

A prime example is the method of suicide. The drugs to be used will be specified in regulations. Barbiturates are most commonly used in other countries. However, there is no consensus on the most effective drug or combination of drugs. Specific drugs, doses and monitoring vary. Reported complications in oral ingestion include vomiting, regurgitation, seizures, prolongation of death and regaining consciousness after ingesting lethal medications.

One assumes that a sufficiently large dose will be prescribed that ensures death. The Bill provides that the coordinating doctor need not be in the same room as the patient who takes the substance. Hopefully, thought will be given to the possibility of a bereaving spouse or partner also taking some of the substance as part of a suicide pact.

The Bill is silent on whether legal aid will be available to support people without financial means and legal knowledge to make the required High Court application. Is this new right of assisted suicide something that in reality only the well-to-do can avail themselves of?

It is a question that brings to mind Anatole France's observation that, 'The law, in its majestic equality, forbids rich and poor alike to sleep under bridges, to beg in the streets, and to steal loaves of bread.'

Remarkably, the High Court judge who considers the application is not obliged to hear from the person in question and there is no right of appeal if the judge decides that the conditions for physician-assisted death are satisfied (presumably on the balance of probabilities, albeit it is a matter of life and death).

The judge must hear one of the doctors. How confident can one be that they have verified that family members and professional carers have no evidence to give which contradicts their view that the patient's wish is clear and settled and no coercion or pressure has been applied? The Bill provides only that the doctors must, if they consider it 'appropriate', 'advise' the patient to discuss their request with their next of kin; and 'advise' them to inform their GP that they are requesting assistance to end their life.

These provisions respect the medical duty of confidentiality and recognise that some patients may not wish family members or carers to be informed of their request. The price to be paid is that family members and GPs who have contradictory evidence are not consulted and vital evidence is not obtained.

It is striking that the Bill proposes an old-fashioned exclusively medical framework. The assessments are provided by medical practitioners and the Act is to be 'monitored' by the Chief Medical Officer. No provision is made for the person, or family members, to be supported by a social worker or solicitor.

Why is that important? Without legal advice the patient may be unaware that their death now will cause significant difficulties for their loved ones because they have not made a Will, or result in their family losing their home or tenancy, the voiding of a life insurance policy or financial hardship. Proper legal arrangements need to be in place for the future care of minor children and disabled dependent adults living at home, and they need to be supported to come to terms with a parental suicide. It could be that the person's apparent 'clear, settled and informed wish' to end their life now is no longer clear or settled once they have been informed of the consequences for others.

A rare but serious complication will occur where the patient is pregnant and their suicide will involve the child's death, sometimes late in pregnancy. Is that permitted by the scheme and is it morally acceptable?

What role will private clinics and the private sector play? The drafting is ambiguous but potentially a significant one. It seems likely that specialist private assisted dying clinics will offer a co-ordinating and independent doctor service, and substitute second opinions where the original independent doctor's opinion is that the conditions for assisted suicide are not met. Unless there is a comprehensive NHS service, the poor may be excluded by cost and in all cases the profit element may distort decision-making.

If the coordinating doctor is ‘unwilling’ to continue in the role, perhaps because of misgivings, the Bill seems to provide only for the appointment with the patient’s agreement of a replacement coordinating doctor. There does not appear to be a means by which a doctor who provided a statement that the conditions are met can rescind it. If that is correct, it is dangerous.

The assisted suicide process cannot proceed if the patient loses capacity at any stage of the process, whether because of their terminal illness or for any other reason. However, capacity is a notoriously slippery and flexible concept and this is likely to be problematic, particularly after the High Court has declared that the requirements for physician-assisted suicide are satisfied. The Bill does not provide for the matter to be returned to court, so at that stage one might have to contemplate a contested application under the Mental Capacity Act 2005.

The Bill if passed will divide the United Kingdom insofar as assisted suicide is permitted in England and Wales but not in Scotland and Northern Ireland. This is because the Bill only applies to persons ‘ordinarily resident’ — an often troublesome concept — in England and Wales for at least 12 months.

There appears to be no clear, close scrutiny of assisted suicides after the event. In the *Mortier* case, the European Court of Human Rights stated that the positive obligations on states to protect the right to life require the existence of ‘a posteriori’ (after the event) control and supervision offering all the guarantees required by Article 2 (Right to Life). The Bill provides only that the Chief Medical Officer must ‘monitor the operation of the Act’ but they are not, it seems, specifically obliged to scrutinise each individual case for compliance after the event. Furthermore, a Coroner is not under a duty to investigate a death simply because it is an assisted suicide.

The Bill has served the useful purpose of focusing attention on the need for society to address the issues of assisted suicide and euthanasia. However, much more careful thought is required before we open this Pandora’s Box. A Royal Commission or Law Commission report, or equivalent, involving extensive consultation, is sensible before we decide to sanction and so normalise state and physician-assisted death. That is the appropriate way forward, accompanied by a government commitment to place a Bill drafted by the Commission before Parliament on a free vote.

There is a time to legislate and a time to refrain from legislating.

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