

End of Life Assistance (Scotland) Bill**David Braine**

Observation about my personal situation:

I note that **I come within one of the categories specified in the Bill**, namely that I have since 1977 been **permanently incapacitated** with paralysis from the eighth rib level downwards owing to a complete break in my spinal cord in a motor accident at the level Thoracic 7/8, and owing to complications in the upper part of my spinal cord **dependent for three times weekly nursing care in manual evacuation of my bowel and for caring assistance in getting up and going to bed since 1984**. **Since 1982, I have also been dependent on others for all shopping and use of motor transport**. In 1984 and 1986 I had periods in the Cornhill Mental Hospital, Aberdeen, with psychosis (auditory hallucinations and paranoia) ascribable to periods of months, in 1986 four months, with very little sleep, **in which it would be true that “I found life intolerable”**, fatigue, severe unrelieved pain, depression and disappointment conspiring together. Probably very few long living paraplegics do not have long periods of the same character of “finding life intolerable”, while afterwards coming to extended periods of vigorous activity and positive quality of life afterwards, periods which they would not have anticipated during their long low periods. Accordingly, I have had more than one period of satisfying the requirements of the Bill for being a “requesting person”.

I will now answer your questions in order.

Question 1: “Do you agree a person should be able to request end of life assistance from a registered medical practitioner?”

No! I do not agree. Any registered medical practitioner should have the right in conscience to refuse such assistance, and refuse to refer the patient to a doctor known to be willing to provide it, since it is not a part of the general duties of a doctor which are to care for the patient’s health, healing, and relief from pain.

Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

No! I am not satisfied.

A person of the age of 16 is unlikely to realise the possibilities in life even if disabled or subject to severe chronic pain or illness. So long as one has one’s voice or any other means of communication it is still within a person’s power to accomplish huge good, possibilities of which increase with modern knowledge of computer aids, and even though what is involved may involve a quite different occupation or vocation than any person might have conceived

apart from his or her injury, disability, pain or illness or the development of the symptoms of some genetic disorder.

Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

No! I am not satisfied.

The inclusion of the “permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable” is very objectionable. There is no definition of “independence”, and the idea of “finding life intolerable” is exceedingly vague, since many people of all kinds especially in a situation of poverty and loneliness in the West would describe a life in this way.

However, in any ordinary sense, most tetraplegics and if they develop complications or as they become older almost all paraplegics would classify as “permanently physically incapacitated to such an extent as not to be able to live independently”, and most are subject to long periods of extreme pain exacerbated by sleep problems and liability to periods of depression, so that few have not had three months periods in which they have “found life intolerable” which would be time enough for the procedures proposed in the Bill to be completed and the person dead. I understate this case, and there are very many with other conditions of which the same would be true, and who within a few years have discovered some *modus vivendi* and new possibilities in life.

Having myself experienced a motor accident and been for six and half months in hospital and then a spinal centre, I became aware that the process of rehabilitation and adjustment takes a long time, and indeed lasts long after one has left the spinal centre. In my own case, the main problems arose from a common complication which was diagnosed after five years and led to a twenty year struggle with pain. The advice of my spinal consultant in 1979, that one had to learn to live and not attend to pain, was advice I took ten years to begin to be able to take, and twelve more to have begun accept. I find that pain forces itself upon my attention, either due to fatigue and sleeplessness, or unrelated illness, or depression, or else to awkwardness in posture. In the course with this struggle with pain the doctors tried a great variety of drugs and I for a long period was a very heavy drinker a week, fortunately never developing any craving for the poison.

In the course of the time since 1986-7, many new activities and ways of fulfilment have emerged which I would never have anticipated.

The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

No! I am not satisfied.

(a) In the last 28 days, after receiving notice that both approvals have been given, the requesting person is liable to be in a situation of terror as to whether he or she has made the choice he or she wants.

(b) There is no provision that any outside person has been witness to or provided the security of independent public advice from general practice or other source that there has been any balance in the description of “feasible alternatives”, “hospice care and palliative care”, or the existence of possibilities in new activities, endurance, etc. or adequate checks on the availability of the relevant knowledge to the witnesses to make judgements about “undue influence”.

Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

No! The safeguards are grossly inadequate.

There is no check that either the designated medical practitioner or the psychiatrist has verified what the requesting person says about his medical condition, and, even if the psychiatrist did so, his report would not be required to mention any evidence that what the requesting person said about his medical condition to the designated medical practitioner (about which he would not be required to be accurately told and there would be no evidence unless it was in writing) was untrue or misleadingly expressed.

Neither any member of the family, nor any friend or person in official relation to the requesting person, nor any public legal authority would have any forewarning of the case until the death had occurred, and there is no provision requiring the registered practitioner to make any enquiry as to whether or not any Welfare Attorney or more Attorney with more general authority has been appointed, and to keep any of these parties informed.

The Bill provides nothing which would provide evidence available to decide whether there had been any conspiracy to do away with the requesting person, relying on his or her being misinformed, or on his or her lacking adequate medical or other advice.

Do you have any other considerations on the Bill not included in answers to the above questions?”

Yes! The bill is objectionable on other grounds.

First further objection

The safeguards in the Bill are so weak as to provide no protection to the disabled, the infirm and the elderly from the psychological pressures created by feeling that their continued living constitutes a burden on others, especially their relatives and any others involved in caring for them, and the struggle to get their will can often be so great as to create a sense of weariness with life, while to a great many of them pain may be endemic with insufficient activities

to get them out of themselves to attend to something else. They often suffer from a sense of loneliness, something alleviated in hospices and good care homes. None of these backgrounds constitutes somebody exercising “undue influence”, but each provides a kind of background to which suicide or voluntary euthanasia constitute false solutions.

Already people, especially the disabled, the infirm and the elderly are often afraid or even terrified of going into hospital in case of hospital infections and of "do not resuscitate" orders, but up until recently they have had a general confidence that doctors, nurses and auxiliary and paramedical workers will not take part in attempts to kill them. And they have had confidence in doctors and these others in the setting of general practice and the home. It is very important that this confidence should not be weakened. **And this is a general reason for the balance of the law being as it is.**

There is a danger of doctors, nurses, and so on, coming to feel under pressure to act against their conscience in going along with the desire of patients or relatives to connive in or support patients and relatives in plans to commit suicide, and this will create over the course of time the need for conscience clauses to protect these professions. **Any change in this situation would constitute a distortion of medical values, and make service as a doctor impossible for a great many people.**

However, more generally, it is vital that value should be continued to be seen in every life including the disabled, the Down's syndrome, the chronically ill and those with short term or long term terminal conditions. There is a danger of the disabled, the handicapped, the infirm and the elderly being regarded as having a human life which is less valuable than that of the vigorous and healthy. Once the life of the disabled and some of the gravely ill is seen as a reason for the ending of this life to be assisted, it weakens the belief in the value of the life of other disabled and gravely ill people who might then be weakened in the disposition to endure and grow in richness of contribution to society through their endurance, patience and capacity to be drawn out to good spirits.

Some of the disabled and terminally ill have produced their most valued work in the period of their disability and sometimes long illness, The experience of learning to calm people and of learning calm and patience from people's endurance and fighting through psychological and physical difficulties can be ennobling and enriching to others in life.

Second further objection: corrupt individuals and the possible distortion of medical training and motivation

Society would have no safeguard against there being individuals registered medical practitioners and psychiatrists who made it publicly known that they were willing to provide “end of life assistance” as described in the Bill.

The Bill provides no controls over the supervision or motivation of such persons.

Further, the alternative, of making it a general service which any registered medical practitioner or psychiatrist could be asked to take part in would involve changes in medical training objectionable in most medical faculties and to most medical doctors, and to most people thinking of training to be a doctor and thinking of this as being occupied in healing, restoration of capacities, and mitigation of evils such as pain, and services ancillary to these such as radiology, anaesthetics, etc.

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11 May 2010