End of Life Assistance (Scotland) Bill

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Introduction
As a medically trained Christian minister and a wheelchair user with Multiple Sclerosis, I intend to give a personal view of this Bill. I state my firm opposition to the Bill and my support for the improvement and widening of the availability of long term care for the chronically ill and disabled and palliative care for the terminally ill.

I responded to the Consultation held last year on the Draft End of Life Choices (Scotland) Bill. I am amazed that, after all the criticisms made during the Consultation, the Bill which has been introduced is so poorly drafted and lacking in rigour. The Bill is so vaguely worded in parts that it can be interpreted in different ways and thus is unsuitable as legislation.

General Comments
1. As someone with a progressive degenerative disease which may well cause me to end up in a totally dependent state, I can empathise with those who face such a prospect or who already are in such a state. However, I do not accept that the solution is to provide the option of euthanasia or physician assisted suicide (PAS) for the small minority who want them to be available. (These two terms seem to be conflated into the vague “end of life assistance” in the Bill.) Palliative Care specialists tell us that once symptoms are well controlled very few patients with terminal illness persist in requesting that their lives be ended. I would also submit that our human dignity is not diminished or destroyed by becoming more dependent on others. I have found that becoming more dependent makes me more appreciative of the loving care and the sheer humanity of those who care for the weak, the vulnerable and the defenceless. The moment we give the option of the quick way out, we devalue the lives of severely disabled, dependent, chronically or terminally ill people, as well as those who care for them. This proposed legislation would lead to pressure being put on such people to consider euthanasia. The patient would be liable to internal pressure because of not wanting to be a burden to others and to external pressure from people with ulterior motives. Society’s attitudes would also change over time as euthanasia and/or PAS became routine and economic pressures would lead more people to see “end of life assistance” as the answer to such distressing conditions. Society, and indeed the National Health Service, would be irrevocably changed and respect for human life would be further reduced.

2. As a medical doctor with 21 years’ experience in medicine and surgery in Scotland and in India I am horrified by the Bill’s assumption that registered medical practitioners should be party to ending a patient’s life actively either by euthanasia or PAS. From the time of Hippocrates, 2,400 years ago, it has been the accepted ethical standard of the medical profession not to administer a fatal dose to a patient. This radical new proposal would have serious effects on the profession and the doctor/patient relationship. It would cause a radical division in the medical profession between those who see
deliberately ending a patient’s life as acceptable and the vast majority who want to maintain life with all the support necessary to reduce the suffering of those who are dying. It could also attract into the profession those who have an unhealthy fascination with causing death (e.g. Dr Harold Shipman). It would undermine confidence in the medical profession as supporters of life. Of course the time does come in the course of an illness when death has to be allowed to supervene, but the doctor should never actively bring about the death of a patient intentionally. Patient autonomy is not absolute. The patient has the right to refuse treatment that he/she considers to be intrusive and distressing and may prolong life only at the cost of increased suffering, but this does not confer the right to demand that the doctor end their life deliberately. The two situations are different.

3. As a Christian minister I believe, along with the adherents of most of the world’s major religions, in the importance of preserving human life, even at its weakest and least functional. From the Christian perspective human beings are made in God’s image and likeness, and this likeness is not diminished by injury, illness, physical or mental abnormality or loss of physical or mental functions. Defence of and care for the weak has always been a cornerstone of the Christian social conscience.

Section by section critique

1. Title, introduction and section 1

The title states that the purpose of the Bill is “to permit assistance to be given to persons who wish their lives to be ended; and for connected purposes”. So, I thought, it must have something to do with either assisted suicide or euthanasia or both. I was then surprised to read the definition of this assistance in 1.2:

In this Act “end of life assistance” means assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.

The definition by itself could just mean palliative care, as it contains nothing about helping people to end their lives. This vagueness is shocking and immediately disqualifies this Bill from being taken seriously as a potential Act. Although it is never stated outright in the Bill, it appears that euthanasia as well as assisted suicide is permitted. The title says that it is for “persons who wish their lives to be ended”, obviously by someone else (euthanasia) and not necessarily by themselves (assisted suicide). “Appropriate means” are never defined, another serious omission. Dying with dignity means different things to different people. Much of this Bill is based upon subjective judgement. The inference of the title and the definition taken together is that only by deliberately ending one’s life can one die with dignity – an insult to those practising and those benefitting from palliative care. At a time when we are trying to stem the tide of suicides among young people who see no point in going on living, this seems a strange note to be sounded in proposed legislation!
2. Need for two formal requests
Since most GPs in Scotland are against euthanasia and assisted suicide, there would have to be made available a list of doctors willing to participate. There is no mention of a conscience clause for doctors and other health workers who do not wish to partake in “end of life assistance” on conscientious grounds. It would appear that doctors who are against euthanasia and PAS would be obliged to refer applicants to a doctor who is prepared to participate. This is unacceptable, since the accompanying Memorandum (paragraphs 113-115) states that the existing General Medical Council guidelines are sufficient to cover this situation: “The GMC guidance is clear, however, and there would be a duty on registered medical practitioners who object to participating to make arrangements to see a registered medical practitioner who would be prepared to consider a request for end of life assistance” (Memorandum, 115). This is an entirely unjustifiable claim, as the GMC guidelines were made up when this situation was not envisaged.

3. Revocability of request for assistance
This is one of the token safeguards in the Bill. It is difficult to see how this could work in practice. An informal request could be all too easily ignored.

4. Eligibility requirements
Sixteen is too young an age for taking such a grave decision.

The 18 month registration requirement could easily be circumvented to allow people from outside Scotland to take advantage of the law.

The two categories of persons eligible for “end of life assistance” give rise to concern. “Terminally ill” is defined as having six months’ life expectancy, but this is very difficult to predict with any degree of accuracy. “Permanently physically incapacitated to such an extent as not to be able to live independently” would include within the scope of the Bill a very large number of people with a wide range of disabling conditions leading to dependency, but not necessarily reduced life expectancy. I find this demeaning to all persons with disability or chronic illness. “Finding life intolerable” is a very subjective judgement and this is deliberately left vague and not further defined, as Explanatory Note 21 makes clear. This state of mind may vary over time, depending on many intrinsic and extrinsic factors and I fear that the proposed time scale and the vetting process, such as it is, would tend to favour a quick decision to end life rather than to encourage supportive and other measures to preserve life.

5. Requirements relating to designated practitioners and psychiatrists
At the moment, doctors are, quite rightly, not trained to kill patients. The central role given to medical practitioners in this Bill implies that they would have to be trained in “end of life assistance”, in other words how to kill people. This prospect fills me with foreboding.

6. Requirements relating to first formal request
The formal request is “for end of life assistance under this Act”. Because this assistance is never clearly defined it is difficult to see what objective meaning such a request could have. Also the signing by a witness seems to be so perfunctory that it could easily become a routine procedure like witnessing any other signature.

7. Consideration of first formal request by designated practitioner

The designated practitioner has to meet and discuss certain things with the requesting person but it seems that he/she need not fully examine or assess the person’s condition. Mere discussion of alternative courses of action such as palliative care is not sufficient. Palliative care must be experienced by terminally ill people before a request for “end of life assistance” is considered. Likewise a full medical, psychological and social assessment should be required for those requesting persons who do not come under the category of “terminally ill”.

The psychiatrist has only to give a “positive” report and the designated practitioner can approve the request. This assumes that every situation will be straightforward, which is far from the real life situation. There appears to be no requirement for consultation and agreement between practitioner and psychiatrist, despite the accompanying Memorandum stating, “The designated practitioner will consider the request along with a psychiatrist …” (173). The burden of decision is on the designated practitioner alone, which is unsatisfactory. The impression one gets is that the Bill assumes that the requesting person has decided already and that’s the most important thing. The whole procedure is designed to grant the person’s request as easily and as quickly as possible with a few token safeguards along the way.

8. Consideration relating to second formal request

The time-limits – a minimum of 15 and maximum of 30 days – are far too short. This would put more pressure on all concerned, especially a vulnerable patient. The second request should be processed by a different practitioner in order to provide a second opinion; otherwise it would become a routine endorsement of the first request.

9. Consideration of capacity etc. by psychiatrist

There seems to be no requirement for the psychiatrist to carry out a full psychiatric assessment. However, “discussion” with the person is not enough. For instance assessment of the possible presence of a depressive illness ought to be looked for specifically, and evidence of internal as well as external pressure being exerted on the person. The exclusion of the effects of drugs or alcohol just because they are not “mental disorders” as defined in the Mental Health (Scotland) Act 2003 is unacceptable, as they could well be important factors in making such a request. As a further safeguard the psychiatrist for the second request should be a different one from the one who examined the person for the first request.

10. Agreement on provision of assistance
The Bill specifies who may not provide “end of life assistance”, but it does not state positively who may provide it. Does this mean that the “designated practitioner” could depute this duty others, perhaps not even medically trained? Would the names of these people be recorded?

The place in which “end of life assistance” is provided is not clearly specified. It appears from the Financial Memorandum in the Explanatory Notes (96-101) that the Bill assumes that that this facility is to be available within the NHS. This radical departure from the traditional function of the NHS is to be deplored. The Memorandum notes that this could actually result in savings for Health Boards because ending a person’s life is cheaper than continuing to treat and care for the person (paragraph 97). This financial saving could very quickly become a determinative factor in decision making in end of life situations as euthanasia/PAS became an accepted procedure.

11. Requirements relating to the actual provision of assistance

One of the serious omissions in the Bill is that, while there are some details about provision, there is nothing about the actual administration of the means of ending life. This omission is both surprising and extremely worrying. The Memorandum, paragraph 109, states, “The means to be used and the method of delivery is [sic] not specified in the Bill.” The reasons given are unsatisfactory, majoring on the individual’s choice and the experience of the designated practitioner. Although the designated practitioner has to be present, there is no mention of who actually administers the fatal means to end life (11.6). This omission must be intentional, because the Explanatory Notes (79) say “regardless of who administers the means to bring about the end of life … the designated practitioner must be present when the end of life occurs.” Distinctions between assisted suicide and euthanasia are intentionally being blurred here. This underlines the grossly unsatisfactory nature of the Bill.

There is no mention in the Bill of the procedure to be followed after an assisted death. The Explanatory Notes (104) state, “It can be expected that COPFS will consider each case of assisted death and instruct investigation into the death.” However, the whole matter of recording, reporting and investigation of assisted deaths should have been dealt with in the Bill. It appears to me that the possible consequences of this Bill have not been thought through properly and this is further evidence of its unsatisfactory nature.

Conclusion

While I oppose the Bill primarily on principle, I also believe it is so poorly conceived and drafted that it should be summarily rejected by the Scottish Parliament. I believe the Bill’s stress on individual autonomy, though attractive to many people who want absolute control over their lives, will, if applied in this way to promote “end of life assistance”, result in the infringing of other people’s rights as society changes its views on the sanctity of human life. The best way to prevent possible abuse of the proposed Bill is not to pass it into law in any form and to ensure the wide availability of good long term and palliative care for all who need them.
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