

# End of Life Assistance (Scotland) Bill

## Submission to the Parliamentary Committee by The Free Church of Scotland

### Introductory Comments

The original Draft Bill was entitled “End of Life Choices (Scotland) Bill”. We responded to the consultation, opposing the Bill on principle as well as criticising its detailed provisions. In the Consultation Document and Draft Bill the emphasis was on individual autonomy and the right to choose “assisted dying”. The change in title reflects a change in emphasis to regulating the activity of some persons, including medical practitioners, who may assist in ending the life of a wide variety of persons who apply for such assistance. However, individual autonomy is still basic to the argument behind the Bill.

Many of our criticisms of the Draft Bill are still applicable. In particular we quote from paragraph 6 of our submission:

**Individual autonomy.** The foundation of the proposed Bill is clearly stated on page 2 [of the Consultation Document] to be “*the principle of autonomy, that the person has the right to determine the quality of his or her own life and its value, unrestricted by the moral, cultural, religious, or personal beliefs of others*”. This would appear to give the individual an absolute right to decide when his/her life has such a quality and value that it should be ended. This extreme individualism ignores the importance of the fact that we humans exist in relationships and in community. We come into the world as completely dependent creatures and we remain dependent on one another to a greater or lesser extent throughout our lives. As well as rights we have responsibilities and duties towards others. The care we exercise towards one another is part of what makes us fully human. We should also learn to receive care as well as give it. It should not be regarded as loss of dignity to be dependent on others. We have no right to demand that someone help to end our life. Deliberately taking a human life is so serious that only extremely grave reasons can be used to justify it, such as, for example, a just war, and even that concept has many problems. Ending an innocent person’s life, even with the purpose of reducing the amount and length of suffering is not justified, especially when good palliative care is available. Our common humanity is best represented and supported by that kind of care and not by deliberately ending a life. We fear that this Bill, if it comes into force, would lessen people’s willingness to care sacrificially for those suffering from disabling, debilitating and terminal illnesses.

As detailed below, we find that the Bill as introduced into Parliament is seriously defective and should be summarily rejected. If, after considering the many trenchant criticisms that emerged in the extensive consultation, the drafters of the Bill could not present a more clearly defined and well-worked out document, this shows either that they are incompetent, or that the Bill is deliberately vaguely drafted, or that it is impossible to frame a satisfactory Bill on this subject.

## Summary of criticisms

- We oppose the Bill on the basis of the principles of the sanctity of human life and the duty of care to the very end of our natural lives. This does not mean prolonging life unnecessarily by intrusive, futile and distressing treatment, but it excludes the deliberate ending of a human life, even with the motive of ending suffering.
- The Bill is poorly drafted and lacks clarity, being full of euphemisms. It fails to specify what exactly is meant by “end of life assistance”, what means of ending life are permitted and who is actually to administer the fatal dose or whatever means are used to end life. As pointed out below, it appears to include euthanasia as well as assisted suicide, although this is not specified.
- The categories eligible for “end of life assistance” under the Bill include a large number of people – not just the terminally ill (again poorly defined) but people with many different kinds of illnesses and disabilities who may “find life intolerable”. The inference is that ending life is a valid ‘treatment option’ in these conditions. This is demeaning and detrimental to the interests of persons with disabilities and chronic illnesses.
- The Bill gives medical practitioners and the National Health Service a key role in the process. We strenuously oppose this perversion of the roles of the doctor and the NHS from that of carer, healer and preserver of life to that of the destroyer of life, however well-intentioned this action may be.
- The decision to end life involves only the “requesting person” and the “designated practitioner”. The role of the psychiatrist is confined to judging capacity, whether the person is making the request voluntarily and whether the person is acting under any undue influence. This is too limited a role and there is no provision for a ‘second opinion’ or any review of the decision.
- The Bill is hopelessly optimistic that the “safeguards” provided will prevent abuse of this legislation. For example, the requirement that palliative care should be discussed with the requesting person is not sufficient (7.1). It should be specified that the person must experience palliative care before a request for “end of life assistance” can be considered, for reasons mentioned below.
- The Financial Memorandum (96-101) accompanying the Bill grossly underestimates the number of people who may avail themselves of the provisions of this legislation. Estimates are based on figures from Oregon (where reporting is voluntary and therefore not exact) rather than on figures from the Netherlands, which would be more realistic given the nature of the Bill, which appears to permit euthanasia as well as assisted suicide. The number of people applying for “end of life assistance” could very quickly run into hundreds and then even more as it becomes a routine procedure.

- Because of this underestimate the framers of the Financial Memorandum (96-101) play down both the financial and time implications for Health Boards, GPs and Psychiatrists and the Crown Office Procurator Fiscal Service. They even make the suggestion that money may be saved by the Health Boards (97)! That, of course, is not the motive of the sponsor the Bill, but it could very quickly become a major factor in decision making.

## Section by section critique

### 1. Title, introduction and section 1

- **End of life assistance** This phrase is in itself ambiguous. It could mean “assistance at the end of life”, which could just signify all the usual help and care, including palliative care, that people need as they approach death. It could also mean “assistance to end life”, which could encompass both euthanasia and assisted suicide. These latter are two well-known and well-defined terms which lack ambiguity, but are nowhere to be found in the Bill. However, the following definition is given 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.

This definition is so vague that it actually hides the meaning which it is supposed to convey! In itself it could just mean palliative care. The phrase “to enable a person to die with dignity and a minimum of distress” is subjective and means different things to different people. The clue to the intended meaning is given in the opening sentence of the Bill. We are told 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”. The assistance is not limited to help to end one’s life oneself, but for one’s life to be ended – obviously by someone else if necessary. The inference is that this is the best (or the only) way to “die with dignity and a minimum of distress” – an inference we strongly dispute.

Furthermore the mention of “administration” as well as “provision” of “appropriate means” would confirm that euthanasia (the administration of fatal means to end someone’s life) as well as assisted suicide (the provision of means to end one’s own life) is permitted. In other words this Bill is a Netherlands-type, rather than an Oregon-type, Bill and encompasses euthanasia as well as assisted suicide.

- **Appropriate Means** Nowhere in the Bill are these means defined. There are many means of causing death. Do these “appropriate means” include administering a poison such as a large dose of barbiturate, an opiate, intravenous potassium chloride or a muscle relaxant, or the introduction of an air embolus into a vein, or suffocation with a pillow or plastic bag? Who is to judge what is “appropriate”? It

appears that it is down to an agreement between the “requesting person” and the “designated practitioner” (10.1.d). Again a large amount of subjectivity is apparent, leaving a wide degree of latitude in the choice of means. This naively assumes that people and practitioners will choose some kind of “dignified” and efficient means of ending life. What if the agreed means fails? Can another means be used without another agreement between the person and the practitioner? The hint is given in 11.1 that the end of life assistance must, “as far as reasonably practicable”, be provided in accordance with the agreement between the requesting person and the designated practitioner. This vagueness is inappropriate in a legislative instrument.

## **2. Need for two formal requests**

It appears that the “designated practitioner” does not need to be the GP with whom the person is registered. This practitioner will not know the requesting person well and will obviously be predisposed to granting such a request, or he/she would not be involved at all. Since it is well known that the majority of doctors in Scotland are not in favour of euthanasia and assisted suicide, we can foresee the emergence of a “list” of doctors who are willing to be involved. Would the person’s registered practitioner have a duty to give that list to the person and also supply him/her with the requisite application form for a formal request? No such forms are mentioned, but it is easy to see such a bureaucratically framed procedure requiring them as the procedure becomes routine.

## **3. Revocability of request for assistance**

This appears to be one of the “safeguards” which are supplied. However, it is not at all clear how effective this would be in practice. It is difficult to see how an “informal” notice could be given to the designated practitioner, even through a third party, if the requesting person was very ill and the designated practitioner not readily available. It could all too easily be ignored. There would have to be yet another form!

## **4. Eligibility requirements**

- Why is the qualifying age not 18, the age of majority? Sixteen is too young.
- The 18 month registration requirement seems to be to guard against people from other countries coming to Scotland to take advantage of the law, but this could be circumvented in various ways – non-residents could register in advance with a private practice set up for this purpose. There is no stipulation in the Bill that registration must be with an NHS General Practice.
- The two categories of persons eligible are loosely defined. “Terminally ill” is defined as six months’ life expectancy, but this is notoriously difficult to predict accurately. “Permanently physically incapacitated to such an extent as not to be able to live independently” would include a very large number of people with, for example, progressive neurological disorders, paralysis, severe heart or lung disease and many other disabilities, both congenital and acquired. This widens the

ambit of the Bill to people who are not terminally ill and is really an affront to all persons with disabilities. “Finding life intolerable” is a very subjective judgement and depends on many unspecified factors – psychological, emotional, physical and social. This is unsatisfactory, as this state of mind may well fluctuate over time. Yet, as Explanatory Note 21 makes clear, the phrase is deliberately vague and not further defined in the Bill.

## **5. Requirements relating to designated practitioners and psychiatrists**

Why are close friends of the requesting person not excluded from this category also? They too would lack objectivity.

Who is to judge whether the professed ignorance of “relationship, benefit or interest” is genuine?

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 grounds of conscience. The unacceptable inference is that it is a doctor’s duty to consider a request for “end of life assistance” and refer the person to a doctor who has no objection to the procedure. This is confirmed in the accompanying Memorandum (113-115) which states that the existing GMC guidelines are sufficient to cover this situation. This is an unwarranted assumption, as this precise situation was not envisaged at the time the guidelines were drawn up. Indeed “end of life assistance” is such a radical departure from the accepted role of a medical practitioner that it cannot be regarded simply as a “certain procedure” or one of “all the options”.

A further cause for concern is that, at the moment, doctors are, quite rightly, not trained to kill patients. Is it envisaged that there would be specialist training in “End of Life Assistance Medicine” with its own qualifications and protocols?

## **6. Requirements relating to first formal request**

The request is “for end of life assistance under this Act”. Given the vague wording of the proposed Act this is like signing a blank cheque! How can a witness, however knowledgeable and impartial, certify that the person “understands the nature of the request”? We cannot envisage anyone quizzing the requesting person in such circumstances. Those who would know the person’s state of mind best are, quite rightly, excluded from being witnesses. Close friends should also be excluded. We can envisage this requirement becoming a formality, like witnessing any other document that doesn’t have the life and death implications of this request.

The requirements relating to care home employees are unsatisfactory, as they are in a position to exercise influence on the requesting person. Again who is to judge whether professed ignorance of “relationship, benefit or interest” is genuine?

## **7. Consideration of first formal request by designated practitioner**

The designated practitioner has to “physically meet” and “discuss” certain things with the requesting person but there is no requirement to examine the person or medically assess his/her condition. Would the designated practitioner have full access to all records and to relatives and carers who might be able to assist his/her assessment? Despite the conditions to be met it is all too easy to envisage this approval becoming a perfunctory procedure.

Mere discussion of alternatives such as palliative care is not sufficient. Surely palliative care must be provided for and experienced by terminally ill people before a request for “end of life assistance” is considered. It is well known that experience of palliative care usually leads to the person withdrawing a request to have life ended.

Again, “forms of end of life assistance” are not specified. Are there no limits? This is unacceptable.

The psychiatrist has only to give a “positive” report and the designated practitioner appears to be able to approve the request. This assumes that every situation will be clear-cut. 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 both unfair and unsafe.

## **8. Consideration relating to second formal request**

The time-limits are far too short – a minimum of 15 and maximum of 30 days. These limits would put extra pressure on vulnerable people. The first limit should be at least doubled and the second at least trebled. Only a small minority of people have a steely determination which is unalterable. 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**

The role of the psychiatrist is fairly circumscribed and yet ought to require a full psychiatric assessment to make it meaningful. “Discussion” with the person is not enough on which to make such a momentous decision. For instance assessment of the possible presence of a depressive illness ought to be looked for specifically, and evidence of internal pressure as well as external pressure. Why should the effects of drugs or alcohol be specifically excluded just because they are not included under the rubric of “mental disorder” as defined in the Mental Health (Scotland) Act 2003? They could well be important factors in making such a request.

The psychiatrist for the second request should be a different one from the one who examined the person for the first request as a further safeguard.

## **10. Agreement on provision of assistance**

Although the Bill specifies who may not provide “end of life assistance” it does not state positively who may do so. Can they be people who are not registered medical practitioners? Will the name of the person who administers the means of causing death be recorded?

The place in which “end of life assistance” is provided is not clearly specified. Will it normally be an NHS clinic or hospital? The Financial Memorandum in the Explanatory Notes (96-101) would suggest that this is to be a new service provided by the NHS. The thought fills us with horror, especially as the Memorandum casually suggests that this could actually result in savings for Health Boards (the definite inference of paragraph 97).

If private ‘end of life assistance clinics’ spring up, are they to be registered, inspected and controlled or can anyone get into the business? Who will regulate “assisted deaths” at home?

The 2 day ‘cooling off period’ is far too short in such a serious matter.

## **11. Requirements relating to the actual provision of assistance**

While there are some details about provision, there is nothing about the actual administration of the means of ending life, surely a glaring omission. This encourages suspicion that the Bill is intentionally vaguely worded in order to allow a wide variety of approaches. This is further confirmed by the Memorandum, paragraph 109, which states, “The means to be used and the method of delivery is [*sic*] not specified in the Bill.” The reasons given are unsatisfactory, largely centring on individual choice of the requesting person and the “expertise” 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.” The Bill treats this central and most serious part of the procedure with complete indifference. This omission underlines the grossly unsatisfactory nature of the Bill.

There is no mention in the Bill of the procedure following 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.” In the case of suicide this would be so, but if the Bill includes euthanasia, this is not immediately apparent from current guidelines. This omission highlights the deliberate understatement of the radical departure the introduction of this legislation would signify.

## **Conclusion**

While we maintain our opposition to the Bill on principle, we also strongly believe that because of the many defects highlighted above, this Bill should be rejected by the Scottish Parliament. If this Bill were to become law, it would have a detrimental effect on society's respect for human life, would damage the doctor-patient relationship, would be difficult to administer without widespread abuse and would lead to a devaluing of the lives of people who are dependent on others because of disability or chronic illness. We urge Members of the Scottish Parliament to reject it. Instead we would encourage Parliament to continue the excellent work it is doing in promoting the availability of palliative care for all who need it.

Rev Dr Malcolm Maclean  
Convenor  
Communications Committee  
Free Church of Scotland  
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