End of Life Assistance (Scotland) Bill

Joy Elliott

Palliative care doctors, nurses and other staff reject a change in the law to allow assisted suicide and voluntary euthanasia. They reject the End of Life Assistance (Scotland) Bill for the following reasons:

Context of the Bill

Evidence of need for a change in the law

There is no robust evidence to show that a change in the law is required. The policy memorandum cites a few self determined people who have gone to Switzerland to take advantage of the current loophole in Swiss law to allow non-Swiss nationals assisted suicide. The numbers are very small (115 over 8 years).

In addition it cites results of polls to the general public which would appear to suggest that the public is behind a change in the law. The results of these polls need to be interpreted carefully. When faced with a choice between a painful death and an injection to end life it is clear what will be chosen. These choices are likely to be ill-informed and based on fear and ignorance. Research carried out by Market Research Services in 2005 for the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill found that: ‘opinion polls purporting to show that a large majority of people would favour a change in the law are misleading. They are generally based on answers to ‘yes/no’ or ‘either/or’ questions without any explanatory context and without other options-for example, good quality palliative care- being offered and that the results of polls are limited in value and cannot be accepted at face value as an authentic account of opinion within the UK’.

In stark contrast to the above, there is robust evidence to demonstrate the impact of good care. Very few terminally ill people who are cared for by specialist palliative care services make determined requests to be actively helped to die. The National strategy for palliative and end of life care (Living and Dying Well, Oct 2008) provides a structure to significantly improve palliative care services for all. Rather than promote assisted dying, our Government should aspire to adequately fund excellence in care.

For those with severe disability who are not receiving good care and feel life is intolerable the appropriate response is to research, promote and fund better care rather than ending the person’s life. Emotive anecdotes as in the policy memorandum are no basis for a change in the law.

Patient autonomy and the right to a dignified death
Dignity means different things to different people. For most people, modern palliative care ensures a dignified death. Even a difficult death can be dignified. It is wrong to promote the concept that active termination of life is necessary to have a dignified death.

This Bill disregards good evidence in medical literature about the basis of dignity in care, and uses the term loosely, without any attempt to define dignity.

It is important to recognise that patients can retain control over treatment options at end of life if they lose capacity by writing an advance refusal of treatment or appointing a welfare attorney to make decisions on their behalf.

It is worth noting that complications such as failure of completion, myoclonus and vomiting may occur in both assisted suicide and euthanasia in 3-16% of patients.

The Policy Memorandum mentions patient autonomy and the right of the person to seek assistance to die. Autonomy is at least a limited concept, but we do have choice, along with a responsibility to recognise that our choices affect others in society.

Patients may feel they have a duty to request to be killed as they feel a burden to their families. It was shown in Oregon, where assisted suicide has been legalised, that over one third of people who died after ingesting a lethal dose of medication, cited concern over being a burden to others as one of the reasons for this choice. Governments have a duty to promote healthy societal attitudes, and that includes the concept of bearing the burdens of others, particularly those who suffer. It is an unhealthy attitude to promote the taking of life in such circumstances.

Such legislation would influence societal approach to the care of disabled people, blunting the value currently placed on the importance of human life, whatever the disability. Furthermore there is real potential for this in turn to influence funding of care, which as the accompanying documents state explicitly, would be more expensive than the cost of ending life. Should this Bill become law, our society will have crossed a clearly defined line which separates what has long been agreed is morally right from that which is wrong. The line would become much less clear as there are eligibility criteria to be met which are, by definition, discriminatory as not everyone who wants to take advantage of a change in the law will meet the criteria. It seems likely that this inequality would prompt future relaxation of the criteria, as has already happened in Holland.

The Bill

Title and involvement of doctors
The title of the Bill is misleading. ‘End of Life Assistance’ is provided by palliative care and active termination of life plays no part in this care. Giving this title to the Bill is an attempt to soften the reality of what is proposed. It should more honestly be entitled ‘the Euthanasia and Assisted Suicide Bill’.

It is assumed in the Bill, without specific and focussed consultation with the medical profession, that doctors are the right people to be involved in this process. There is very little justification for this. It is a societal issue and is not driven by the medical profession. If society wants the law to change, a way needs to be found for implementing this change without depending on doctors who, in the main, do not want to be involved and who, contrary to the assertions, do not possess expertise in ending life. Medical care seeks to promote life and health, and these proposals fundamentally undermine that principle. Health care should play no part in this process.

The Bill is silent on the issue of conscientious objection. The accompanying notes imply that the GMC guidance that currently exists would place an obligation on a doctor who wants to opt out of this to contact a doctor who does not. However it is unclear if the guidance as it stands now would be relevant in the context of ending life as this does not seem to fulfil the GMC guidance to respect life and promote health.

**Scope of Bill**

Margo MacDonald has indicated that her Bill would be based on the Oregon model which allows Physician Assisted Suicide. However this Bill is in fact based on the Netherlands model which allows both euthanasia and physician assisted suicide although is more restricting. From the figures from the Netherlands, many more people (3,700 each year) take advantage of euthanasia than of assisted suicide (300). The previous proposals in Scotland by Jeremy Purvis concerned assisted suicide only. The wording of the 2010 Bill is couched in such terms that the inexperienced eye is unlikely to pick up that it proposes euthanasia and therefore the proposals should be more transparent.

Lord Joffe put forward a proposal in England in 2005 to legalise assisted dying and a Select Committee was set up which made recommendations when that proposal failed.

**Recommendations from the House of Lords Select Committee following Lord Joffe’s Assisted Dying for the Terminally Ill Bill in 2005**

In Scotland there is no obligation to take cognisance of these recommendations but as there was a significant consultation that took place to inform the recommendations it would be wise to have taken them into account when drafting this Bill. However several of these recommendations have been disregarded, eg
1 A clear distinction should be drawn in any future Bill between Assisted Suicide and Euthanasia in order to examine the implications of both separately.

2 Any future Bill should set out clearly the actions which a doctor may and may not take in providing assisted suicide or euthanasia

3 If a future bill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis

4 Patients should experience palliative care and not just have a discussion about it before agreement is reached to terminate life

5 Assessment of psychiatric disorder (e.g., depression) should be part of the psychiatric assessment and not just assessment for capacity

6 Any new Bill should not place on a physician with conscientious objection the duty to refer an applicant for assisted suicide or euthanasia to another physician without such objections—it should provide adequate protection for all health care professionals involved with an application.

It is unsafe to assume that law, once drafted, will always be enacted as expected. Some members of the Select Committee specifically warned of the legal challenges which could develop around the practicalities of enacting this law.

‘Once they are on the statute book they have a habit of causing collateral damage well beyond the target area’ (Lord Carlile of Berriew) \(^4\)

‘The medical profession is there to treat, cure and care for sick and disabled people. Once lawyers get involved the whole premise changes: bitterness, strife and serious money take over, families are divided, and suspicion reigns. Doctors should steer clear of assisted suicide – or more accurately of putting people to death- if they want to retain the trust of their patients.’ (Julia Cumberlege, former health minister, House of Lords) \(^5\)

**Provision or administration of appropriate means**
The Bill makes no recommendations on what will be allowed regarding appropriate means, and only requires that the means should be those agreed between the doctor and the requesting person. This could include ways of killing that do not involve lethal drugs. Whilst the Bill likely intends death to be drug-induced, it does not state this. The loose phraseology could legitimise many effective but undignified ways of causing death.

**Designated Practitioner**
This is described as a registered medical practitioner: doctors engaged in practice now need to have a licence to practice. This is a point of fact but we do not condone involvement of doctors at all.

Eligibility requirements

1  **16 years or over**
We think this is too young. The issue to be considered, however, is patients’ suffering, assessment of need and the provision of care rather than age.

2  **Registration with doctor for 18 months**
This could be abused if a person is determined enough. Registration does not require domicile. The type of practice is not defined in the Bill and it there is a potential for a private practice to be established for the purpose of assisted dying.

3  **Diagnosed as terminally ill (less than 6 months to live)**
This is almost impossible to determine with sufficient accuracy, especially with non-cancer diseases. In Oregon, where the same requirements exist, it was found that prescriptions of lethal medication were given in accordance with the law but many people did not take them and some survived for up to 2 years.

4  **Life intolerable**
This is subjective and many people find life intolerable for some part of their illness. Most come to terms with it and cope well in time and can find life enriched and relationships strengthened. They will be denied this if the law changes.

5  **Physically incapacitated so as not to be able to live independently**
Most people need others to survive in their lives: even mild disability could be acceptable under this criterion. This Bill puts disabled people specifically at risk here. When they find life intolerable, they should be supported and helped, not killed. Law should protect the vulnerable, not expose them to greater harm.

Safeguards

We believe that the safeguards are not likely to prevent abuse or prevent vulnerable people, who can see no reasonable alternative, choosing to end their lives. It is vital that anyone who supports a patient who chooses this course of action knows the patient well and understands the patient’s true wishes. Most doctors will want to opt out of this process and therefore the patient may be referred to a doctor who does not know them. The psychiatrist will not know the patient at all. Unless these doctors spend a lot of time with the patient they are unlikely to know whether the patient’s choice is not being unduly influenced or coerced by others or by societal expectations. The designated practitioner is the same for both the first and the second request and the psychiatrist, in practice, is also likely to be the same. There is no requirement for the psychiatrist and the
designated practitioner to agree on the course of action. So, whereas the Bill would seem to incorporate a second opinion from the psychiatrist, this is fatuous.

Resource constraints may mean that the interviews will not be as frequent as they need to be. The psychiatrist is expected to assess the person’s capacity, the voluntary nature of the request and the absence of undue influence. Influence can be internal (for instance, depression) and external (for instance from relatives or carers). Full assessment for depression is not mentioned specifically as a requirement and it should be. Two formal assessments by the psychiatrists would probably identify major mental illness in most cases, but for some it would be inadequate. The proposals are unsafe for more difficult cases for whom careful multidisciplinary assessment along with corroborative evidence from people who know them would be necessary to determine mental health.

The exclusion criteria for witnesses may mean that they may not know the patient and family issues adequately. Their requirements are similar to that of the psychiatrist. How are they to know if the patient understands the nature of the request, is making the request voluntarily and is not acting under any undue influence? This is very complex and many people will not understand the issues involved. There is a requirement for the patient to sign the first formal request. If they are severely disabled, how is this to be achieved if they are unable to write?

The rapidity with which this momentous process should be executed and completed is particularly alarming.

Each death under the act may be reported to the Fiscal. However, Dutch experience demonstrates that almost 50% of cases are not reported to the authorities. The Fiscal is only required to consider each case and it is expected that most cases will not be investigated. Thus the Bill does not appear to incorporate the level of scrutiny during or after the event which must surely be obligatory for an action of such gravitas.

In summary, this Bill lacks the detail essential for the introduction of responsible law. It bases its case on questionable principles and fails to explain why its provisions meet the purported need. It largely ignores wise advice about the drafting of such legislation, and the gravity of what it proposes is cloaked in ambiguous language. It displays a woeful ignorance of the principles and practice of medicine, and of palliative medicine in particular. Whilst acknowledging the need for safeguards, those it proposes have little rigour. It leaves material factors open to speculation and crucial questions unanswered. Good law should address a real need, protect the majority, and respect those on whom it depends for its enactment. This Bill does none of these things and should be rejected.

As a Palliative Care Counsellor I have great concern for both the patient and there families should this Bill be considered.
While the focus is on the patient we must also be aware of the long term impact on the family, this Bill goes no where to address this issue.

References

2. Groenewood et al. NEJM 2000; 342: 551-6
4. The Times, 5th November 2008
5. BMJ 2009; 339:b3422

Joy Elliott
Palliative Care Counsellor
7 May 2010