End of Life Assistance (Scotland) Bill

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The issues behind the Bill are complex and can be difficult to conceptualize and verbalize. The information in the public domain, particularly the wording of the Bill and the accompanying explanatory notes promotes misinformation and a number of misconceptions that require further clarity and consideration. Some of these will be presented here in addition to answering the important questions raised in relation to various elements of the Bill as proposed.

Definition of Terms

Paragraph 1(1) a: “end of life assistance”
This term includes physician assisted suicide (PAS) and euthanasia. Most of the discussion and debate in society has revolved around PAS. In the public interest and to ensure informed debate the real meaning of “end of life assistance” needs to be made **explicit**.

Paragraph 1(2): “to enable a person to die with dignity and minimum distress”
The Bill makes no attempt to define “dignity” or “dying with dignity” yet the term “dying with dignity” is becoming synonymous with PAS and euthanasia, the implication being that a natural death is not dignified and equally must be distressing. This is reinforced in several places by the policy memorandum. Paragraph 12 introduces the notion that facilitating death should be allowed to avoid "torturing lingering pain", paragraphs 62-65 which focus on “suffering” all refer to “dying in pain”.

These comments all reinforce a fear of death, a belief that it is prolonged and painful, sustained largely through a **lack of knowledge** of modern palliative medicine and perhaps memories of people who died without adequate palliative care.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

It is **through this approach** that people can be assisted to die naturally with dignity and minimum distress.

Requesting Assistance

Paragraph 2 (and 6) The formal requests must be approved by a registered medical practitioner
Concern has been expressed over the **form of the formal requests**. This requires clearer definition and if this were to include a visit to a solicitor,
considerable time, money and effort could be involved. The requesting person still has to be well enough and capable of signing written requests and agreements separated by a significant period of time. The minimum period of 15 days could be considerably longer, especially if there is a delay in psychiatric assessment after the first request. In many parts of Scotland there is a substantial waiting time for initial outpatient psychiatric assessment.

**Paragraph 3(1) Revocability of request for assistance**

The period of ‘notice’ for revocation ‘however informal’ is not determined and could be open to misinterpretation.

Would natural expressions of concern about whether someone is doing the right thing or not at the time of death count? If they were to count – this may inhibit people from having open discussion and actually increase distress due to the inability to discuss fears. If they were not to count – conflict could arise between the patient and doctor or family and doctor if they were to be misinterpreted.

**Eligibility Requirements**

**Paragraph 4(1) Age limit for request**

The Bill would permit people as young as 16 years to request assistance to die despite the fact they are legally protected from marrying without parental permission or buying a glass of wine. Consideration needs to be given to additional safeguards to prevent an impulsive decision to request assistance to die from a determined teenager.

**Paragraph 4(2) (a) and (b): “finds life intolerable”**

The Bill makes no attempt to define intolerable. The emphasis in the memorandum paragraphs on suffering is again on a notion of dying in pain. Paragraph 47 and 48 of the memorandum states that for “a small number of patients, perhaps suffering from Huntingdon’s or virulent MS or Parkinson’ (that) palliative care at the end of life does not accomplish a dignified death” and that they have a “prolonged period of misery as they approach death”.

People who are ‘permanently physically incapacitated’ and ‘unable to live independently’ are eligible. This would include those with chronic illnesses such as arthritis or diabetes or physical disabilities that render them to need assistance with activities of daily living or personal care but who have otherwise independent and full lives. The level of dependency or inability to live independently requires definition.

**Requirements relating to designated practitioners and psychiatrists**

**Paragraph 5(2) (b) Payment of reasonable fees**

If payment of reasonable fees is to be made for work done in relation to provision of end of life assistance and, it is noted, assessment may not be able to be made in one visit, is this not a conflict of interest? If no fee is payable then how can proper assessment (which may require multiple visits) be ensured, especially if private assessments need to be carried out due to
NHS waiting times? If in future, clinics are set up to facilitate the process, these will certainly have a financial interest in approving requests.

Requirements relating to the request for assistance to die

Paragraph 6(2) and (4) Witness statement
The requesting person has the indignity of asking 2 witnesses, who are not family members or likely to benefit from their estate, and explain to them that they want to have assistance to die.

Unrelated witnesses may not be in a position to know that the request is made voluntarily and without undue influence.

We only need to consider how many capable adults are victims of domestic abuse (there were 49,655 incidents of domestic abuse reported in Scotland in 2007/8) to realise that capable adults may be vulnerable and put in positions they do not choose and from which they feel they cannot escape. It is unreasonable to expect that witnesses or doctors may be able to detect all cases of people under ‘undue influence’ in their request for an assisted death. In addition, due to the time restraints between first and second requests, even well-meaning relatives may prompt their loved ones to submit the second request believing this is what they want.

Concern is also expressed regarding how much undue influence society may exert over people in such situations to request assistance to die. This is of great concern given the current economic climate and the information in paragraphs 97 and 110 of the Explanatory Notes regarding the reduced cost of delivering an assisted death versus provision of ongoing medication and care.

In addition, the number of expected assisted death requests (and therefore the cost to the Crown Office Procurator Fiscal Service), may be questioned if figures are extrapolated from the situation in Holland rather than Washington and Oregon. If the numbers are correct, why put the majority of vulnerable people at risk for the benefit of a few?

Paragraph 8(2) and 11(2) & (6)
The same ‘designated practitioner’ must deal with both formal requests and be present at the time of death. There are implications to the patient if the designated practitioner is unavailable e.g. on annual leave or sick for the duration of the approval validity. The requesting person may have to go back to the beginning of the process through no fault of their own.

Provision of assistance to die

Paragraph 10 Means of assistance
What “means by which that assistance is to be provided” should be included here? There need to be safeguards to limit the means available and ensure that they are reliable and effective and free of side effects.
Requirements relating to the actual provision of assistance to die

Paragraph 11(4) Person providing end of life assistance
Consideration needs to be given to protecting the person nominated or requested to assist in the death of another. Undue influence could be exerted on them to assist a terminally ill friend.

MSPs may wish to consider what support people providing assistance may need to receive afterwards and additionally, what screening of people present and assisting before and after the event may be required.

Interpretation

Paragraph 12 Involvement of relatives
There is a duty placed on the doctor to be able to ascertain the identity of people present and assisting in the death. How would the doctor be able to ensure they are not in any way related to the person or potential beneficiaries? Surely this is a judicious issue which, if formal checks by police are to be put in place, is likely to further reduce the dignity and increase the distress at the end of life.

Paragraph 83 of the Explanatory Notes states that the purpose of the Bill is to ensure a good and dignified death but this is not defined at any point and it is not clear why this cannot be realised naturally which is the situation for many people already.

Availability of appropriate care

The Bill is largely supported by people with progressive degenerative neurological conditions who unfortunately have not traditionally experienced specialist palliative care or had the same investment in resources or research as those with a malignant condition. There is a real risk that the Bill promotes within society the misconception that nothing can be done to relieve end of life suffering.

There is also a real risk the Bill will in fact prevent investment in developing and expanding the availability of the kind of care aimed at conserving dignity and relieving existential/spiritual suffering at the end of life. The Bill further promotes within society the notion of hopelessness and futility of the lives of our most vulnerable without adequate emphasis on enhancing and valuing life right up until the moment of death.

The explanatory notes and policy memorandum both state that the Bill is about offering choice at the end of life and that it is not intended as an alternative to palliative care. A good choice is usually an informed choice and the Bill currently does not facilitate this.
Experience of Palliative Care

There is no requirement in the Bill for the requesting person to have experienced any palliative care, only that they are informed about it (quite likely by a non palliative care medical practitioner who may well not be fully informed of resources available). It is widely recognized within palliative care that to be told about palliative care is not the same as having experienced it – a fact born out of the testimonies of many patients.

Many patients are apprehensive before their first contact with palliative care services. This is partly a result of the fear of talking about and thinking about death—a fear which is prevalent in society and drives much of the discussion surrounding requests for assistance to die.

Our fears surrounding death and dying can be better addressed by promoting open discussion of the issues and by the provision of appropriate care and support.

References to support the evidence presented in this submission are available by request.

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