End of Life Assistance (Scotland) Bill
Royal Society of Edinburgh (RSE)

Advice Paper 10-06

Summary

- The Royal Society of Edinburgh (RSE), Scotland’s National Academy, welcomes the opportunity to comment on the End of Life Assistance (Scotland) Bill. Concern for the sanctity of human life divides opinion. While some vigorously support the right of individuals to take control over their own death, others have strong reservations over the impact this would have on end of life relationships. Parliament needs to come to a clear view on the basic issues of principle – whether it should be legally permissible for anyone to assist another person to die.

- It must be recognised that this Bill has ramifications for both individuals and society that are far from ordinary. The RSE suggests that consideration be given to taking a ‘toe in the water’ approach and including a clause that commits the Scottish Parliament to a re-debate in five or ten years’ time. Such a re-debate would be significantly better informed.

- The RSE draws attention to the scope of the Bill as set out in Section 1. Reference to a ‘person’ who provides end of life assistance clearly indicates that this does not have to be a doctor, making the Bill the first in the UK to go beyond physician assisted suicide.

- Furthermore, Section 1(2) indicates that the provision of the means of assisted death and the administration of such means are interchangeable whereas in popular and quasi-legal terminology the former is classified as assisted suicide and the latter as euthanasia. The inclusion of euthanasia again broadens the scope of the Bill further than most existing legislation elsewhere. The intention to do this must be made clear.

- We believe that the Bill gives too much power and responsibility to the medical profession. Whilst medical expertise is required to certify a person’s physical condition, the final decision is not a medical one. A panel of carefully selected and trained lay people from a diverse range of professions could be equally appropriate. In the specific area of defining, or failing to define, who is to provide or administer the means, however, it could be argued that the Bill gives too little importance to the role of medical expertise.

- The categories of and criteria for eligibility for assistance in dying set out in the Bill are generally satisfactory as a starting point but great care must be taken with the terminology used. We believe that these would benefit greatly from a re-debate if a ‘toe in the water’ approach was taken.
We have reservations over the requirement that an individual must have been registered with a medical practice in Scotland for 18 months. We believe that this carries a significant cost as it excludes those who have legitimately come to Scotland for other reasons and been struck by a debilitating or terminal disease. This cost should be weighed against the perceived benefits of this safeguard.

The RSE advises that the Bill should contain an express provision in respect of the certification of death resulting from end of life assistance.

Introduction

1. The Royal Society of Edinburgh (RSE), Scotland’s National Academy, welcomes the opportunity to comment on the End of Life Assistance (Scotland) Bill. The expertise of the Society’s Fellowship in ethics and philosophy, religion and society, the provision of health services and medical law has been used in constructing this advice paper.

The principle of end of life assistance

1. The End of Life Assistance (Scotland) Bill attempts to set out the steps and processes through which an individual should be able to seek end of life assistance. We suggest that the logical discussion of the Bill should be a two-step process. It should firstly determine whether in principle it should be legally permissible for anyone to assist another person to die and, if it should, whether the Bill contains effective and proper measures that will deliver the benefits that are sought without undesirable consequences that have the potential to outweigh them.

2. It should also be born in mind that there is a wide diversity of deeply philosophical, ethical and religious views on the subject. Parliament should be sensitive and respectful to such views, and if it determines to proceed, give cogent reasons why it does so. A possible precedent that the Committee might consider is that of the Warnock Committee of Inquiry into Human Fertilisation and Embryology. This was a matter of profound importance that involved deeply held views about the propriety of using new reproductive technologies. The fact that these issues had been probed and reported upon with deliberate seriousness made it easier for Parliament to make a decision that satisfied public concern that it had been treated with proper diligence.

3. Those who support the Bill accept the principle on which it is based: that if a mentally competent person who finds their life intolerable because they are terminally ill or permanently incapacitated seeks assistance in carrying out their decision to end their life, it should be legally permissible for another person to provide that assistance. By making such assistance permissible, subject to strict safeguards, the law takes account of the interests of those who wish to seek such help, and of the compassionate motives of those who may want to provide such help.
4. Many who have reservations about the principle of the Bill are particularly concerned about the impact that the legal permissibility of end of life assistance might have on end of life relationships. The right to request such assistance would be held at individual level, but it may well lead to a change in the dynamics of networks and societal relationships more widely. Safeguards may attempt to prevent pressure from being placed on an individual to request end of life assistance by family members but the existence of such an option may burden that person’s thinking about what is best for his/her family regardless. The provision of such assistance could also have significant implications for other societal relationships, such as the traditional role of medical professionals. The costs and benefits to both individuals and society of legalising end of life assistance must be properly considered and balanced.

5. We now comment on whether the Bill as proposed addresses these issues in a practicable legal form.

The End of Life Assistance (Scotland) Bill: a ‘toe in the water’ approach

6. It must be recognised that this Bill, introduced into the Scottish Parliament in January 2010, is far from the ordinary in respect of its ramifications. There are few black and white answers to the questions it raises and it is difficult to predict the impact that its proposals might have on individuals and communities should it become law. In light of this, it is suggested that consideration should be given to including an explicit clause that would require a re-debate of any resulting legislation in, for example, five or ten years’ time.

7. While this would be a highly unusual step, the RSE believes that a ‘toe in the water’ approach is eminently suitable for such a fundamental piece of legislation. A re-debate would be significantly better informed than is possible at present in the absence of practical experience. It should be made clear that the re-debate could lead to anything from the repeal of the existing statute to the extension of initial provisions to a wider range of cases.

8. The proposals set out in the current draft of the Bill raise numerous issues for consideration. We comment on a number of these below. Ultimately however there are questions that can perhaps be answered best only when there is practical experience on which to draw. These include questions on where the boundaries should lie in respect of who is and is not eligible to request end of life assistance, the role of the medical profession in the process and the efficacy of the safeguards proposed.

Scope of the End of Life Assistance (Scotland) Bill

9. Section 1 of the Bill is striking for two reasons. Section 1(1) refers to a ‘person’ who provides assistance in dying, with no requirement that a medically qualified practitioner carry out the final act of assistance. The
possibility that this is an intended omission is given some credence in the terms of section 11 which, taken to the extreme, could open the door to a profession of “euthanasist”. As far as we are aware this is the first Bill introduced in the UK that has attempted to extend legally assisted death beyond the confines of physician assisted suicide (PAS). As such, the Bill is entering into unknown territory and must be treated with great care.

10. Section 1(2) also appears to advance the scope of the Bill to a greater degree than has been attempted elsewhere, as it defines end of life assistance as “including the provision or administration of appropriate means”. The implication is that these two methods are interchangeable when in fact it is widely recognised that the former, the provision of the means for assisted death, is what is understood as assisted suicide, whereas the latter, the step of actual administration, is classified as euthanasia.

11. It may be argued that there is no substantial moral distinction between the two approaches, and therefore no legal distinction is needed. Furthermore, we appreciate that cases may arise in which an individual has requested, and been granted, end of life assistance, but is physically incapable of self-administering the means that are provided. However, the RSE believes that if the intention of the Bill is to extend its scope to include euthanasia then this must be made clear in the text.

12. As a minimum we suggest that S1(2) be amended along the following lines:
   ‘In this Act, end of life assistance includes:
   a) the provision of appropriate means or
   b) in the event of the requesting person being physically unable to utilise such means, the administration of appropriate means so as to enable…’

The role of the medical profession under the End of Life Assistance (Scotland) Bill

13. The Bill as it currently stands gives an excessive amount of power and responsibility to doctors and we have deep reservations about the role that the medical profession is being expected to play. Whilst we agree that medical expertise is needed to certify a terminal illness or permanent physical incapacity, we do not accept that the decision on whether it should be permissible to provide assistance is a medical one any more that it is a legal, ethical, or even a religious, one. Indeed, in light of the traditional role of medical practitioners to preserve life, doctors should perhaps be protected from having to make the final decision.

14. We suggest that further consideration be given to the process through which a formal request is approved. Given the steps set out in the Bill, how will a valid, cohesive judgement ultimately be made? What is the forum in which the various reports can be considered? Who will take ownership of the ultimate decision and where will the records be kept? How will appeals
or differences of opinion between professionals be handled? Whilst medical opinion will feed into this process there is no reason for the medical practitioner to take responsibility for it. A lawyer or social worker would be equally appropriate, or even a small panel of carefully selected and trained lay people. Indeed, such a panel would have the benefits of quickly gaining experience through on-going involvement and ensuring a level of consistency in decision making.

15. If responsibility is to remain with the medical practitioner we would highlight a number of issues. Firstly, the high degree of influence the doctor would have in the process would allow them to impose their own morality in making a decision in response to a patient's request. Consideration should be given to how this risk could be minimised and how any appeals might be handled if patients did not agree with the practitioner's assessment or application of the criteria. Furthermore, medical practitioners should have the right to refuse to take part in the process without needing to give reasons for this refusal.

16. Secondly, we would suggest that in Section 2 – and elsewhere as appropriate in the Bill - a medical practitioner should be defined as a medical practitioner holding a current licence to practise and that consideration should be given to specifying a required minimum level of experience. Finally, consideration should also be given to the creation of a central list of psychiatrists and medical practitioners who would be trained and licensed specifically to provide end of life assistance. We note that ultimately this may not be a practical approach in respect of medical practitioners as a patient is more likely to want his or her own doctor. We would also draw attention to our previous comments on the role of medical practitioners, questioning the reliance on doctors to make the final decision. However, if medical practitioners are to be given this pivotal role, a central list would again help to ensure consistency in how criteria are applied.

Categories and criteria for those requesting end of life assistance

Categories
17. Section 4(2) sets out the two categories of individuals eligible to apply for end of life assistance:
   a) a person who has been diagnosed as terminally ill and finds life intolerable; or
   b) a person who is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable.

18. These categories are generally considered to be an acceptable basis from which to start. We raise a number of concerns however, that in practice these may prove restrictive and exclude individuals to whom end of life assistance might properly be extended.
19. For example, should an individual who is permanently mentally incapacitated have the opportunity to indicate their wish for end of life assistance before their illness reaches a stage at which they become incompetent to make such a decision? Indeed, should there be scope for anyone of sound mind and legal age to make a formal 'living will' in which they indicate their preference should they become mentally incapable of making such a request (noting that safeguards and a formal process would have to be considered to make this possible)? Should someone who has been diagnosed with a terminal illness and finds life intolerable but has a life expectancy of one year be made to suffer for longer than someone with a life expectancy of six months? Indeed, should the criteria be limited to the terminally ill when it could be argued that it is the intensity and the intractability of pain that is the measure of intolerability? These are questions that may benefit from a re-debate if a 'toe in the water' approach was taken with the current Bill.

**Terminology of categories and criteria**

20. The terminology used in the Bill must be considered with great care. The judgement of whether or not life is tolerable will be entirely subjective and therefore the emphasis on whether the patient himself 'finds' life intolerable is very important. The Bill should not create a situation in which it forces a standard opinion of what is or is not tolerable on an individual or leaves it to a third party (medical practitioner, psychiatrist or other) to make that decision based on specific criteria.

21. However more guidance would be welcome on what is meant by 'not able to live independently'. In this case, without being too prescriptive, it would be useful to have examples of what is considered dependent and clarification on whether this is meant to be limited to physical dependence or include mental, or even social (such as can be the case with drug addicts, for example), dependence.

22. Furthermore, we suggest that the wording be amended to make absolutely clear that for the patient who has been diagnosed with a terminal illness or physical incapacity, it is for this reason that they find life intolerable. This may help to safeguard against potential requests for end of life assistance arising from a person’s finding life intolerable because they consider themselves a burden on others due to their illness or incapacity.

**Medical uncertainty**

23. It is important to recognise that medical judgements on the life expectancy of terminally ill patients or on the extent of permanent physical incapacity can be uncertain and subjective. This should be reflected in paragraphs 20 and 22 of the Explanatory Notes.

**Age**

24. Section 4(1)(a) sets the legal age for requesting end of life assistance at 16. This may prove to be an emotional barrier to the Bill’s passage given the care and love lavished on the raising of children, and a consequent reluctance to concede the life of someone who many would regard as a
child and who is not yet an adult according to statute. If the Bill is treated as 'toe in the water' and the age raised to 18 there may be less resistance to the proposals.

25. However it is important to bear in mind that in practical terms a person of 16, or one who is deemed able to make informed judgements, can already decline medical treatment. This is sometimes the case for those as young as 14. The question is, however, whether anyone – child or otherwise – can be said to ‘understand’ death and therefore whether the criterion applies.

Residence in Scotland

26. We note the requirement in Section 4(1)(b) that a person requesting end of life assistance must have been registered with a medical practice in Scotland for a continuous period of at least 18 months prior to that request. We understand that the rationale for this may be to overcome political, and potentially public, concerns over “suicide tourism”.

27. We believe that this is an issue that must be handled with care. An obvious cost of this requirement is that someone who has recently moved to Scotland, only to be struck by a debilitating or terminal disease, will not be able to seek assisted death. This is problematic because all the arguments in favour of end of life assistance apply just as forcefully in this sort of case as in the case of someone who meets the requirement.

28. We suggest that careful consideration is given to weighing the costs of including this requirement against its perceived benefits. More information is required on how many people could be expected to travel to Scotland to take advantage of the Bill should it become legislation. Furthermore, there is a debate to be had on whether “suicide tourism” is indeed a bad thing as it is clear that an individual who has decided to travel abroad for this purpose will not have taken the decision to end their life lightly. If the principle that an individual who finds life intolerable, through terminal illness or permanent physical incapacity, has the right to request end of life assistance is accepted, as it would implicitly be with the passing of this Bill, then it would apply equally well to people who have come to Scotland to end their lives as to those who happened to be here in the first place.

29. Even if it is decided that a requirement to deter travel to the country specifically to take advantage of this legislation should be included in the Bill, we would suggest that some thought be given to balancing this with the significant cost of excluding those who have recently moved to Scotland for other reasons. Would six months be a sufficient period to deter those who may travel simply to request end of life assistance? Should the requirement be only that the individual prove residence in Scotland for a period of 18 months? Should it be possible for a person to circumvent this requirement by proving that they came to Scotland for a legitimate reason, such as an employment opportunity?
Certification of death following end of life assistance

30. Current medical jurisprudence stresses the importance of protecting the public from the maverick doctor and we consider it particularly important that assisted deaths are monitored by efficient death certification so as to ensure that the criteria are being followed. While there is some reference to this in the Financial Memorandum of the Explanatory Notes, the Bill itself is silent on the matter and we see this as a lacuna that should be filled. It seems self-evident that neither the designated practitioner nor the assisting person, if he or she be a medical practitioner, should be empowered to certify the fact and cause of death and it follows that all deaths arising within the Act should be reported to the fiscal. We would advise, even if for no more than the avoidance of doubt, that the completed Bill contains an express provision to this end.

Additional information

This response has been prepared by an expert RSE working group and signed-off by the General Secretary on behalf of the Society.

Any enquiries about this submission and others should be addressed to the RSE’s Consultations Officer, Ms Susan Bishop (evidenceadvice@royalsoced.org.uk).

Responses are published on the RSE website www.royalsoced.org.uk

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