End of Life Assistance (Scotland) Bill

Lord Mackay of Clashfern

Introduction

1. Margo MacDonald’s Bill is seeking to legalise assisted suicide and voluntary euthanasia for persons who are terminally ill or are “permanently physically incapacitated to such an extent as not to be able to live independently”\(^1\) and who also find life intolerable.

2. In 2004-05 I chaired a select committee of the House of Lords of the Westminster Parliament which examined a similar bill tabled by Lord Joffe\(^2\). This bill was similar in many respects to that recently tabled by Margo MacDonald in the Scottish Parliament, the main difference being its narrower ambit – Lord Joffe’s bill was limited to persons who were terminally ill. In the hope that it will assist the deliberations of the committee examining Margo MacDonald’s bill, I offer below a summary of expert evidence received and conclusions reached by the Westminster select committee in respect of certain parts Lord Joffe’s bill that closely resemble aspects of Margo MacDonald’s. As it is not my intention to comment on the suitability or otherwise of the latter bill, I submit this evidence as a factual account rather than in the form of responses to the questions posed in the call for evidence.

The Westminster Select Committee

3. The select committee spent some six months examining both the underlying principles and the detail of Lord Joffe’s bill. During this time, in addition to taking evidence in London, the committee visited the US State of Oregon, where physician-assisted suicide was legalised in 1997; The Netherlands, where physician-assisted suicide and physician-administered euthanasia were legalised in 2001; and Switzerland, where assisted suicide was legalised in 1942, though not specifically as a medical procedure. The committee received over 60 written submissions from interested organisations and took oral evidence from over 140 expert witnesses in the UK and the three other legislatures. In addition, it received over 14,000 letters or emails from members of the public.

4. The committee did not finish its work in time to enable the bill to make progress in that Session and agreed that its report should summarise the evidence received and draw attention to those respects in which any subsequent bill should seek to correct what were seen as deficiencies in Lord Joffe’s bill. The committee’s report was published on 4 April 2005 as HL Paper 86 of Session 2004-05. It is available online at the Parliament website\(^3\) and provides the basis of the comments that follow.

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\(^1\) Section 4(2)(b)
\(^2\) Assisted Dying for the Terminally Ill Bill 2004
\(^3\) http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.
Evidence and Conclusions

Terminal Illness

5. Margo MacDonald’s bill defines a person who is terminally ill as someone who “suffers from a progressive condition and if death within six months in consequence of that condition can reasonably be expected”\(^4\). This definition is similar to that which appeared in Lord Joffe’s bill\(^5\), so it may be instructive to look at what expert witnesses had to say about it.

6. Diagnosis and prognosis are expert processes, and perhaps for that reason many of us tend to regard them as exact sciences. The select committee was told, however, that they were far from being that. The Royal College of Pathologists pointed to a consistent 5% error rate, revealed in post mortems, in diagnosis of terminal illness. They wrote that “almost all histopathologists (doctors who perform post-mortem examinations) have experience of cases deemed to have died from an untreatable terminal illness, but post mortem examination discloses another condition – that would have been treatable – for the patient’s death”\(^6\).

7. The difficulties of making an accurate prognosis – ie predicting the course of a diagnosed terminal illness – were, the select committee was told, even greater. Medicine was described as “a probabilistic art” and there was a general consensus that, while reasonably accurate prognoses could be made when a patient was within days or a few weeks of death, the scope for error at six months was considerable. Indeed, it was not uncommon for patients given six months’ life expectancy to live for two or three times as long or even longer.

8. The select committee’s conclusion was that “there is clearly a difference between the popular view of terminal illness, which employs phrases like ‘three months to live’, and the reality of clinical practice, in which prognosis is far from being an exact science and in which there can be wide variations from an overall norm”\(^7\). We recommended that, “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”\(^8\).

\(^4\) Section 4(4)
\(^5\) “terminal illness means an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient’s death within a few months at most”
\(^6\) HL Paper 86, Volume II, Page 730
\(^7\) HL Paper 86, Volume I, Paragraph 250
\(^8\) HL Paper 86, Paragraph 269(c)(iii)
Mental Capacity

9. Margo MacDonald’s bill requires that a person requesting assisted suicide or voluntary euthanasia should have “capacity” to make the request. It defines capacity as “not suffering from any mental disorder which might affect the making of such a request”. Lord Joffe’s bill required an applicant to be “competent”, which it defined as “having the capacity to make an informed decision”. The two requirements are therefore broadly similar.

10. The select committee’s expert witnesses warned that “the desire to die covers a spectrum of intent” and that “far more people express a desire to die than actually make an attempt to kill themselves”. Our attention was drawn to the presence of “episodes of reactive depression as a result of a diagnosis of life-limiting illness” and to “a significant incidence of moderate to severe depression and anxiety at various stages throughout the course of many diseases”, measurement of which could be confounded by the symptoms of the diseases themselves. We were told of research that indicated that “the will to live and the desire for death fluctuate throughout the course of terminal illness for all except a very small number of patients”.

11. We were also advised that, in the case of patients with neurological conditions, there was a significant risk of “cognitive impairment”, which could be difficult to detect. All were agreed that any applicant for assisted suicide or voluntary euthanasia should be referred for thorough psychiatric evaluation, with other professionals – eg neuropsychologists or palliative care physicians – involved as necessary. The select committee endorsed these conclusions, adding that, where evidence of mental disorder was apparent, treatment should be offered.

Finding Life Intolerable

12. Margo MacDonald’s bill requires, as a condition for approval of assisted suicide or voluntary euthanasia, that an applicant “finds life intolerable”. In this respect it resembles closely Lord Joffe’s requirement that an applicant for what the bill called ‘assisted dying’ must be “suffering unbearably”.

13. There was consensus among our witnesses that “unbearable suffering” was necessarily a subjective term and that, if it were to provide any sort of effective filter for assisted suicide or voluntary euthanasia, a patient’s statement that he or she was “suffering unbearably” needed to be confirmed as a reasonable and permanent state of mind. This would require, in the opinion of the National Council for Hospice and Specialist
Palliative Care Services\textsuperscript{15}, a longer relationship between doctor and patient than was required under Lord Joffe’s bill. In other words, for this condition to be at all effective, the physician’s assessment would have to be based on personal knowledge of the patient over a period of time. Other witnesses pointed out that unbearable suffering, while real enough, might not derive from the presence of terminal illness but from concomitant circumstances (for example, the loss of a loved one) and, moreover, that many people who are not terminally ill – or even ill at all - feel they are suffering unbearably.

14. The select committee considered that the definition of an applicant’s suffering needed more objectivity than was provided for in Lord Joffe’s bill. It recommended “unrelievable” or “intractable” suffering as a more satisfactory criterion. In our report we offered the view that “a test of ‘unrelievable suffering’ might ensure than an application would not be taken at face value but that action would be taken to attempt to relieve any suffering and that only in those cases where this was unsuccessful would assisted suicide or voluntary euthanasia be considered further”\textsuperscript{16}.

Implementation

15. The select committee was concerned that Lord Joffe’s bill did not specify clearly what actions a physician might and might not legally take to give effect to an approved application for assisted suicide or voluntary euthanasia. The bill spoke simply of a doctor “assisting a patient to die”. The committee recommended therefore that any future bill “should spell out what a doctor may and may not do in circumstances where an applicant has met all the specified criteria and made a formal declaration”. It should “set out the procedures under which a prescription for lethal medication may be given and the necessary drugs obtained, along with the responsibilities, rights and immunities of the persons involved, such as doctors and pharmacists”. Similarly, “we would expect to see a detailed procedure for establishing whether a request fell within tightly-defined criteria for voluntary euthanasia rather than assisted suicide and, in the event that it did, for putting the necessary action into effect”\textsuperscript{17}.

16. Margo MacDonald’s bill appears to present similar difficulties in this respect to Lord Joffe’s. Though a general definition of ‘end of life assistance’ is given in Section 1(2)\textsuperscript{18}, nowhere is it stated what form “the provision or administration of appropriate means” may or may not take or what other forms of ‘assistance’ might be legal. Though a registered medical practitioner is placed at the centre of the assessment and approval process, his or her precise responsibilities after the approval of an application are not made clear.

\textsuperscript{15} Now the National Council for Palliative Care (NCPC)
\textsuperscript{16} HL Paper 86, Volume I, Paragraph 256
\textsuperscript{17} HL Paper 86, Volume I, Paragraph 248
\textsuperscript{18} “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”
17. It would also appear that under Mrs MacDonald’s bill the choice between assisted suicide and voluntary euthanasia is to be left for agreement between the applicant and the registered practitioner, whereas Lord Joffe’s bill provided for voluntary euthanasia only where the applicant was unable to end his or her own life via assisted suicide. Given the much higher death rate from voluntary euthanasia than from assisted suicide where these practices have been legalised, the committee may wish to consider whether Margo MacDonald should be invited to introduce a similar limitation into her bill.

Conscientious Objection

18. Margo MacDonald’s bill, unlike Lord Joffe’s, does not appear to make any provision for doctors who may have a conscientious objection to assisting a suicide or administering voluntary euthanasia. This is a surprising omission and Mrs MacDonald will no doubt wish to consider what amendment should be made to her bill to cater for those doctors, possibly the majority, who would be unwilling to implement its provisions.

19. In doing so, she may wish to take note of the select committee’s observations on Lord Joffe’s bill as regards conscientious objection. The select committee had noted an observation by the Joint Committee on Human Rights that requiring a doctor with a conscientious objection to refer a patient seeking ‘assisted dying’ to another physician, as Lord Joffe’s bill required, could itself constitute an infringement of conscience. Recognising this difficulty, Lord Joffe undertook to include a more satisfactory conscience clause in any successor bill.

20. However, the select committee made two further observations in its report. The first was that other health care professionals than physicians, including nurses and pharmacists, could find themselves caught up in one way or another in implementing assisted suicide or voluntary euthanasia. Any conscience clause would need to protect their positions as well as that of doctors. The second was that care of the terminally ill is often a matter of multidisciplinary teamwork, with doctors of different specialities working together as equals. The select committee recommended therefore that the drafting of any conscience clause would need to cater satisfactorily for situations such as, for example, where a doctor with primary responsibility for a patient wished to respond to a request for assisted suicide or voluntary euthanasia but other members of the care team had reservations.

Waiting Time

21. Margo MacDonald’s bill requires that, following final approval of a request for ‘end of life assistance’, the applicant and the designated

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19 See HL Paper 86, Volume I, Paragraph 243
20 HL Paper 86, Volume I, Paragraph 262
21 HL Paper 86, Volume I, Paragraph 263
22 Section 10(3)
practitioner must agree on how that approval is to be implemented and it stipulates that “the agreement does not become effective until the expiry of at least two clear days from the date of its conclusion”. Lord Joffe’s bill required a ‘cooling off’ period of 14 days, though this was to be counted from the date when the application was lodged rather than approved.

22. The select committee had reservations about the shortness of Lord Joffe’s proposed ‘cooling off’ period. Though it was recognised that an approved application need not be acted on at once, the committee considered “that, in the patient’s own best interests, he or she should be prevented from acting without reflection – or even from feeling subconsciously that, having proceeded as far as the signing of a declaration and having put a number of people to a lot of trouble, he or she should not draw back”23. Witnesses had drawn attention to the need for a pause so that a patient could stand back from focusing on the process of applying for ‘assisted dying’ and reflect on the decision itself.

23. This reservation is particularly relevant to Margo MacDonald’s bill, which prescribes both a minimum and a maximum waiting period between the two stages of the application process – the second application for ‘end of life assistance’ may be made only if “a period of at least 15 and not more than 30 days has elapsed from the date when the requesting person was informed of the approval” [of the first application]24. The committee examining the bill will wish to consider whether the setting of a maximum time limit could have the unintended effect of pressuring applicants to press ahead with a project on which they have embarked but on which they may have flickering reservations.

Conclusion

24. There are many similarities between the MacDonald and the Joffe bills, the main difference between the two being the wider scope of the former. In the preceding paragraphs I have drawn attention to what the 2004-05 Westminster select committee heard from expert witnesses and concluded about some of the features that the two bills have in common. I hope this perspective will be of assistance to the committee in its deliberations on Margo MacDonald’s bill.

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23 HL Paper 86, Volume I, Paragraph 260
24 Section 8(1)(c)