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Submission from the authors of
Death by Appointment: A Rational Guide to the Assisted Dying Debate

Introduction

1. We write as co-authors of the above book, published in 2020 by Cambridge Scholars Publishing. Professor Baroness Finlay is a specialist in palliative medicine and was a Member of the House of Lords Select Committee which in 2004-05 conducted a thorough investigation into the subject of assisted dying under the chairmanship of former Lord Chancellor Lord Mackay of Clashfern[1]. Her co-author, Robert Preston, is a former senior civil servant and parliamentary clerk. Our aim in this submission is the same as that of our book – namely, to explore in a reasoned and rational manner the many aspects of this complex and controversial issue.

Parameters of the Inquiry

2. The committee's call for evidence states that it will "*focus on the health care aspects of assisted dying/assisted suicide*". While this focus is understandable given the committee's parliamentary remit, the subject of 'assisted dying' goes far wider. In particular, the questions posed in the call for evidence make no mention of the law – how it works and whether it is in need of change. If the committee proposes to investigate the subject of 'assisted dying' as a whole rather than simply its health care aspects, this wider context needs to be examined. While therefore we have adhered strictly to the questions posed in the call for evidence, we feel obliged to observe that this provides an incomplete picture and that other aspects of the debate need to be addressed.

The Committee's Questions

Palliative Care

3. Britain is an acknowledged world-leader in this branch of medicine. It has been a recognised medical speciality here (like, for example, oncology or paediatrics) since 1988 with four years of intensive training required to reach consultant level. By contrast, in many other countries, including those where assisted dying has been legalised, palliative care is either unrecognised or only recently-recognised as a specialist branch of medicine. Indeed, the Mackay Committee was told during a visit to Oregon that legalisation of assisted suicide there had been "*in some ways a vote of no-confidence about some aspects of end-of-life care*"[2].

4. Where palliative care can be improved in Britain is principally in its availability. The high-quality service that we have is not distributed evenly across the country. There are currently shortfalls in specialist staff at all grades. Palliative care, funded principally through charitable donations, has only recently been included as a service that must be contracted for by all Integrated Care Boards. These resourcing and organisational problems can sometimes result in high-quality palliative care services not being accessed or being accessed too late to improve quality of life.

Evidence from overseas

5. Assisted suicide (ie supply of lethal drugs for self-administration by a requesting patient) has been legalised in certain US States. In Canada and in Benelux countries, euthanasia (ie

[1] The committee's report is referred to in this submission in the interests of brevity as The Mackay Report

[2] House of Lords Report 86-II (Session 2004-05), Page 281

administration of lethal drugs to a requesting patient) is also legal. Oregon's assisted suicide law has hitherto been the model advocated by campaigning groups in Britain.

Numbers

6. Oregon's total population is less than half that of London. In the 25 years since its assisted suicide law came into force Oregon has seen a twenty-four fold increase in deaths from this source. Oregon's 2021 death rate from assisted suicide would translate into some 3,350 such deaths annually in England and Wales if a similar law were to be enacted here.

7. Where administered euthanasia has also been legalised, the rise in numbers has been more rapid and much larger. In Canada between 2020 and 2021 the number of such deaths increased by nearly a third to reach a total of 10,064, of which only 7 were from assisted suicide. Canada's current (and rising) death rate from its 2016 'Medical Aid in Dying' law, if reproduced in England and Wales, would result in over 17,000 such deaths annually.

Doctor-Shopping

8. With a majority of Oregon doctors unwilling to participate in assisted suicide, requests are often considered by a small number of willing doctors who have never met the applicants before and have only their case notes to assess whether or not they meet the legal conditions. In 2021 the median length of the doctor-patient relationship for those who took their own lives with legally-supplied lethal drugs was just 5 weeks. Some participating doctors are writing multiple prescriptions for lethal drugs. According to the latest official report, in 2021 one Oregon doctor wrote one eighth of all such prescriptions.

Reasons

9. In Oregon the two principal reasons given by those seeking assisted suicide were losing autonomy (93%), reduced ability to enjoy life as before (92%) and loss of dignity (68%). Inadequate pain control, the reason most often cited by pressure groups for legalisation, comes well down the list at 27%. Worryingly, however, over half of those seeking assisted suicide said they were afraid to be a burden on their families. A similar picture emerges of those seeking assisted suicide or administered euthanasia in Canada.

Professional and Ethical Considerations

10. Following a 2020 poll of its members, the BMA changed its stance from one of opposition to assisted dying to one of neutrality.

11. However, there are two important caveats. When the votes were analysed by the BMA, it was found that majorities of members whose work brought them into close and regular contact with terminally ill patients, including palliative medicine doctors, geriatricians and GPs, were opposed to legalisation, while respondents who had voted for legal change contained a majority of retired doctors, medical students and those in branches of medicine which involve little or no contact with terminally or otherwise incurably ill patients.

12. Moreover, when asked whether, if the law were to be changed to permit assisted dying, they would be willing to participate in such acts, a majority said they would not. It is likely therefore that, if the law were to be changed, we would see repeated here the doctor-shopping and multiple prescribing that has been experienced in Oregon.

13. Any assisted dying law should contain a 'conscience clause' releasing any individual or health service organisation from an obligation to participate. There are, however, concerns based on the experience of other jurisdictions (eg Canada) of pressures to participate being brought to

bear on unwilling doctors post-legalisation. We suggest below[3] that medical involvement in any assisted dying regime should be limited to providing information on the strictly-medical aspects of a request to a separate judicial process.

14. However, ethical issues go beyond the willingness or otherwise of doctors to participate. Patients too are affected, as the question arises whether legalisation could undermine doctor-patient trust.

15. The doctor-patient relationship is a highly asymmetric one in which doctors, with their greater knowledge and experience, are at an advantage. Patients, particularly those with terminal conditions, can be anxious about what lies ahead of them. They can often be in despair and may even in desperation ask for 'something to end it all'. They can make such requests safe in the knowledge that their doctors cannot knowingly and willingly bring them harm.

16. Worried patients often gauge their situations through the reactions of their doctors, whether through body language, tone of voice or words. Under an assisted dying regime a patient is vulnerable to misinterpreting a doctor's willingness to consider a request for lethal drugs as confirming his or her fears that in the doctor's professional opinion death is the best course of action. The patients who step out of the pages of assisted dying proposals tend to be strong-minded and no-nonsense individuals who know what they want and are not vulnerable. But this paints a misleading picture of terminal illness and of the strains, internal and external, that it involves. Incorporating the deliberate ending of a patient's life into medical practice changes the dynamics of the doctor-patient relationship significantly.

Criteria

17. It is important to distinguish between criteria and protections. The criteria are the conditions which an assisted dying law might set for access to lethal drugs. Protections are the procedures which such a law must put in place to ensure that those criteria are met.

18. Where other jurisdictions have set criteria for assisted dying, they have usually included conditions such as decision-making capacity and absence of coercion. Where they have differed is in regard to the nature of any underlying illness (for example, should there have been a terminal diagnosis and prognosis?) and whether administered euthanasia should be included as well as assisted suicide. As noted above, pressure groups for legal change in Britain have hitherto limited their campaigning to legalisation of assisted suicide for terminally-ill people who have received a prognosis of six months or less.

19. Whatever the criteria, they are by their nature arbitrary and as such are open to challenge. Laws, like nation states, are more secure when their boundaries rest on natural frontiers. The existing law rests on just such a frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about the deaths of others. Once exceptions are made to that principle, like terminal illness, the boundary of the law becomes just a line in the sand, easily crossed and hard to defend. There is ample evidence of this in jurisdictions that have legalised assisted dying, most notably in Canada.

Protections

20. As noted above, any assisted dying law must not only set criteria but also spell out the minimum steps which must be taken by law in order to ensure that those criteria have been met. This cannot be left, as some have suggested, to subsequent codes of practice. Protection of the vulnerable is a crucial pre-condition of any assisted dying legislation and Parliament

[3] See Paragraphs 21-22

cannot properly be asked to approve such a law until it has seen not only the criteria required for lethal drugs to be supplied or administered but also the minimum actions that must be taken to ensure that those conditions have been met and satisfied itself that they are fit for purpose.

The Role of Doctors

21. Diagnosis of terminal illness and predicting its likely course relies on assessing the balance of probabilities, a process for which doctors are fitted by their professional knowledge and experience. However, their ability to make reliable judgements regarding other criteria – for example, decision-making capacity, personal or family pressures, settled nature of a wish to die – is doubtful. So, are doctors the people who should make these decisions? This is a particularly important question in today's world of severe workforce shortages and multi-doctor GP practices, where home visits are rare and patients often see many different doctors and nurses with differing, if any, levels of familiarity with their overall situations. Add to this the likelihood that only a minority of doctors would be willing to participate in assisted dying and the phenomenon of doctor-shopping would appear.

22. In our view, if assisted dying were to be legalised, consideration of requests should be placed in the hands of a scrupulously-impartial body with experience of assessing evidence from a range of expert sources, including doctors, psychiatrists, social workers and others, as well as from applicants themselves, and reaching an overall judgement. This points clearly to the courts and, given the gravity of what is involved, to the High Court. Doctors would provide the Court with information on the strictly-medical aspects of a request, a role they already play in other contexts. But it would be for the Court, and for the Court alone, to consider the overall picture in light of evidence from this and other sources and to be the sole arbiter of whether a request should proceed.

Terminal Illness

23. Diagnosing terminal illness is one thing: predicting its course and the patient's remaining life-span is much more problematic. The Mackay Committee was told by the Royal College of General Practitioners that "*it's possible to make reasonably accurate prognoses of death within minutes, hours or a few days*" but that "*when this stretches to months, then the scope for error can extend into years*"[4]. The Royal College of Physicians stated that "*prognosticating may be better when someone is within the last two or three weeks of their life*" but that "*when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor*"[5]. In Oregon many recipients of lethal drugs are living beyond – in some cases well beyond – their six-months prognoses before swallowing those drugs. How long they might have lived if lethal drugs had not been supplied to them is anyone's guess. A much tighter condition would be appropriate in any assisted dying law here – a prognosis expressed in, at most, weeks rather than months.

Mental Capacity

24. Recent attempts to change the law have proposed that capacity should be interpreted in accordance with the Mental Capacity Act 2004 (MCA). However, the MCA states that a person must be assumed to have capacity unless it can be shown that that is not the case. That cannot be a suitable basis for an assisted dying law. A wish to end one's life is usually and reasonably regarded as a symptom of mental distress. Any provision for capacity assessment must therefore proceed from the principle that the presence, not the absence, of capacity must be established.

[4] House of Lords Report 86-I (Session 2004-05), Paragraph 118

[5] Idib

25. Capacity is decision-specific. The level of capacity required must reflect the gravity of the decision in question. A person may have capacity for some decisions but not for others. A request for lethal drugs must be seen as lying at the top end of any spectrum of gravity.

26. Capacity assessment is, moreover, about more than simply establishing whether a person is fully *compos mentis.* It must also take into account the person's situation. It is hardly surprising that terminal illness involves a high incidence of concomitant depression[6]. This, together with any personal or family issues which may be having a distorting effect on the applicant's judgement, must be considered.

27. For all these reasons any regime for assisted dying must include mandatory assessment by a professional psychiatrist. The notion espoused in recent assisted dying bills that an applicant should be referred for such professional assessment only in cases of doubt has been shown to fail in Oregon[7].

Freedom from Pressure

28. Clearly no one who is under pressure of any kind to end his or her life should be supplied with lethal drugs. But identifying such pressures can be difficult. Elder abuse is a significant and growing phenomenon and often goes undetected. A person who has requested lethal drugs as a result of pressure from family members cannot be expected to admit to the fact. Such external pressures need not be malicious: they can range from short tempers resulting from frustration at caring for an elderly relative to not-so-subtle hints that an elderly parent should consider calling it a day.

29. Nor is external coercion the only kind of pressure involved here. In today's environment of rising costs and crisis in social care, families can experience serious economic difficulties if one member has to give up work to care for an ailing parent. It is hardly surprising therefore that seriously ill elderly people can feel internal pressures to 'do the decent thing' and spare their families a care or a financial burden[8].

30. These are serious risks, and judgements of whether or not there is coercion at work cannot simply be left with a doctor, and especially one to whom an applicant had been introduced solely for purposes of assisted suicide and who knows nothing of the family dynamics that may exist behind closed doors. These are personal and social rather than medical judgements and most doctors are in no position to make them.

Informed Decision

31. Previous assisted dying proposals have included a requirement that a request for lethal drugs must be fully informed. No one would dispute that, but informed decision-making goes beyond just informing applicants for assisted dying of what is involved. As Help the Hospices[9] told the Mackay Committee:

    "*Experience of pain control is radically different from the promise of pain control and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking*

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[6] See, for example, the discussion of this subject in Paragraphs 123 to 126 of House of Lords Report 86-I (Session 2004-05)

[7] Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. Ganzini L et al, British Medical Journal 2008;337: a1682

[8] See also Paragraph 9 above

[9] Now known as Hospice UK

assistance to die without having experienced good symptom control could not be deemed fully informed"[10].

32. Specialists in hospice and palliative care not infrequently see patients whose symptom relief has been inadequate and who sometimes talk of 'ending it all' but who, after receiving treatment in hospices or specialist palliative care units in hospitals, have their symptoms stabilised and are able to lead more fulfilling lives. There is a strong case therefore for requiring that persons seeking assisted dying should be required to experience modern specialist palliative care.

Conclusion

33. We have answered the committee's questions to the best of our ability within the tight space constraints set. However, we feel we must repeat what we wrote at the outset – that the questions listed cover only a part of the debate on assisted dying and are largely focused on *how* rather than on *whether* the law should be changed. Licensing doctors to supply or administer lethal drugs would constitute a major change to the criminal law. Analysis of what the existing law says and how it operates is therefore an essential part of any inquiry.

34. Moreover, the parameters set by the committee appear to take for granted that implementation of any assisted dying law should be placed on the shoulders of doctors. Yet, quite apart from any consideration of the additional pressures this would impose on an already heavily-burdened health service, the judgements involved are only partially clinical in nature and doctors are ill-placed to make many of them. We question therefore the assumption that judgements beyond those of a clinical nature should be made by doctors.

35. We stand ready to supplement this submission with oral evidence if invited to do so.

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[10] House of Lords Report 86-I (Session 2004-05), Paragraph 258