Association for Palliative Medicine

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Briefing on Baroness Meacher's Bill by the Association for Palliative Medicine of Great Britain and Ireland https://apmonline.org

The APM is the world's largest representative body for doctors practicing or interested in Palliative Medicine. We offer the APM's perspective because our members core practice is care for those at the end of life.

Summary

"Assisting Dying" (AD) is a loose term that covers assisting suicide and administering euthanasia. Baroness Meacher's Bill is vague, ambiguous, and silent on many key issues. This is remarkable for legislation that changes fundamentally a doctor's duty of care: it contains no safeguards to exclude errors, bias, or criminality; it leaves the door wide open to relaxing safeguards and eligibilities in the future, including bringing in euthanasia; there is nothing in the Bill to protect people at vulnerable times in their lives, and particularly elderly or disabled people. There is no attempt to fill the existing shortfall in specialist palliative care that experiences of bad deaths show to be so badly needed.

Over 300 people a day suffer unnecessarily due to lack of access to these services. During the pandemic palliative care was widely called upon to help. yet it remains a statutory service that is neither funded nor commissioned across the NHS. Most service funding is through voluntary donation. Legislation also signals that the UK is abandoning efforts to improve care of the dying. We urge Parliamentarians to reject this Bill. Some of our concerns are outlined below.

Consequences of legislating for assisted dying

AD fragments good palliative care services because their philosophies are incompatible - Oregon [1] and Canada [2] demonstrate this. Jurisdictions worldwide that involve doctors directly in AD have seen disinvestment in palliative care, except Switzerland where AD is independent of healthcare [3]. Growth in services in Belgium and the Netherlands has stopped since 2012 where AD continues to rise [4] [5] [6].

Evidence from jurisdictions that rely on doctors as gatekeepers on AD also undermine this Bills feasibility and safety. This is not a minor or containable change for healthcare but a paradigm shift in a doctor's duty of care to those with life-limiting disease Every conversation about dying would change after AD as NHS clinicians will have to to discuss the 'full range of options' with patients.

1. **The wording of this Bill is imprecise; the criteria in it are not verifiable and cannot act as true safeguards**

Wishes (S 1(2)(a), 3(1)(a) etc.) ordinarily express the processing of conflicts inherent in facing death. In our experience, they indicate someone articulating concerns and options. Later, the Bill changes language to **intent**. They are different. It is unclear which is meant.

Capacity to decide (S1(2)(c)(ii), S3) is decision and time specific. Assessing capacity to decide to die is momentous and cannot be established safely on a single assessment. The MCA 2005 explicitly excludes its influence on decisions concerning assisted suicide [7]. The Bill does not cover assessment, it assumes that the decision intentionally to end life is no different from any other medical decision. There are no references to tests to exclude coercion, duress, mental health problems or checks to eliminate medical bias and discrimination.

Terminal illness (S2) has no formal definition and can be used to capture most chronic illness as the Oregon Health Dept has admitted [8]. **Medical prognoses** are notoriously inaccurate, even at days to

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weeks. and 'pretty hopeless' at six months [9, 10, 11]. An '**inevitably progressive condition'** is also meaningless as it applies to many medical conditions including normal ageing. This definition allows anyone with an unrelated, overwhelming personal crisis to refuse disease-modifying treatment and to render themself eligible for AD [12]. Patients in Oregon frequently survive beyond 6 months if they have not taken their lethal drugs. Diagnoses are not always right and we regularly encounter patients labelled as dying who are not. No postmortem studies exist of people following AD.

As has happened in the Benelux countries, some pro-euthanasia campaigners in the UK are already campaigning for 'terminally ill' to be removed as a qualifying criterion.

Drugs and their administration are not clear in the Bill.

a. Oregon has tried four different drug mixtures in the past seven years to end life [13]. There is no information on their mode of action nor how they bring about death - affecting heart function or the ability to breath may themselves cause distress. Information is incomplete in Oregon's official reports.

b. The Bill is is silent on a clinician's duty if the patient cannot complete self-administration, whether intravenous administration is forbidden, the action the clinician should take if the patient regains consciousness, experience distress or additional suffering.

2. Parliament is being asked to approve a process with a serious lack of detail

This Bill does not specify how the criteria for the eligibility of lethal drugs will be assessed, nor the process required of the Court. Relegating this to an undeveloped Code of Practice denies Parliament the opportunty to scrutinise proposed changes. The risk is of people's lives being ended in or through error. The Bill's criteria are open to wide interpretation and progressive relaxation, particularly through case law challenges.

a. The minimum ***age*** is set at 18, but does not account for Gillick/Fraser competence. Several countries have widened their criteria to include minors.
b. In the ***decision-making process,*** the Bill is silent on any assessment of ***coercion or duress*** and where responsibility falls to exclude it – untrained clinicians or the Court [14]; the Secretary of State has wide discretion over safeguards[15] including issues such as ***depression or demoralisation*** that may impair decision-making competence[16]
c. ***time frames*** from a 'wish' to die to a court declaration could be as short as a week. As palliative medicine experts, we do not consider this adequate for a reliable, full and safe assessment.
d. The Bill is also silent on ***consultation and disclosure***. Someone could end their life with only medical staff and a judge being aware. The case of Godelieva de Troyer in Belgium, being considered by the ECHR, shows this to be a solid concern [17].
e. ***Other care options:*** There is no minimum standard over information that must be provided, no requirement that the person actually experiences specialist palliative care and its impact, or has received adequate social care provision to mitigate feelings of burdensomeness.

3. Conscientious objection

Experience from other jurisdication[18], and developing English Case Law, has found that conscience clauses offer weak protection [19]. Recent, independent surveys show fewer than 5% of palliative care doctors willing to be involved directly in AD [20] and workforce shortages, have not been considered.

4. **Process and Monitoring**

a. There are no considerations given to the independence of the two medical professionals [21], whether doctors should initiate the discussion, or verifiable obligations and standards of the second doctor, to ensure information was unbiased and clear to prevent AD being discussed at a vulnerable time.
b. A requirement to monitor compliance with the Codes and regulation is absent. There is nothing stipulating minimum reporting requirements in the stipulated annual report, such as details of the person, their diagnosis, mental state, concerns at the end of life, any aggravating factors, the outcome, including complions from the use of lethal drugs, and

c. There is no requirement for external scrutiny.

5. The Court process appears to be a rubber stamping exercise.

There is no information as to who can represent the patient and participate in the Court process, what evidence is required, who has a right to appeal or how the Court is to report its decision.

6. Criminal liability

A person ignoring the Code is not liable to any criminal proceedings, creating the risk of doctors acting without legal consequences. This is exceptionally worrying in the light of rogue practitioners such as Dr Harold Shipman.

The Science and Ethics and Trainees Committees, Executive and President of the APM

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[1] Campbell C, Cox JC. Hospice-assisted death? A study of Oregon hospices on Death with Dignity. *American Journal of Hospice and Palliative Medicine 2012;* 29(3): 227-35.

[2] Harding L. Delta Hospice Society envisions new private MAID free facility. *Western Standard*, 18July 2021: https://westernstandardonline.com/2021/07/delta-hospice-society-envisions-new-private-maid-free-facility/

[3] Arias-Casais N *et al*. Trends analysis of specialised palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliative Medicine;* 2020; 34(8): 1044-56.

[4] RTE Regional Euthanasia Review Committees: Annual reports. See: https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports

[5] Institut Européen de Bioéthique. *Analysis of The Seventh Report of the FederalCommission for Euthanasia Control and Evaluation to the Legislative Chambers(for the Years 2014and 2015)* https://www.ieb-eib.org/docs/pdf/2016-11/doc-1554801216-14.pdf

[6] Second Annual report Report on Medical Assistance in Dying in Canada, 2020. See: https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html

[7] The MCA 2005 S62 states: *For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961 (c. 60) (assisting suicide).*

[8] https://www.mercatornet.com/careful/view/the-watertight-oregon-model-for-assisted-suicide-is-a-leaky-boat/20969

[9] Glare P *et al.* A systematic review of physician's survival predictions in terminally ill patients. *BMJ*, 2003; **327**: 195-8

[10] Agosta F *et al* Survival prediction models in motor neurone disease. *European Journal of Neurology*, 2019; **26**(9): 1143-52.

[11] Warriach HJ *et al*. Accuracy of physician prognosis in heart failure and lung cancer: comparison between physician estimates and model predicted survival. *Palliative Medicine*, 2016; **30**(7): 684-9.

[12] Oregon Health Authority. Death with Dignity Act annual reports. http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx.

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[14] Christopher de Bellaigue The Guardian Death on demand, has euthanasia gone too far?

[15] Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: …in the Netherlands (2012–2016) https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-018-0257-6

[16] Kissane D The Contribution of Demoralization to End of Life Decision making Hastings Centre Reports 2004 https://doi.org/10.2307/3528690.

[17] https://www.telegraph.co.uk/news/worldnews/europe/belgium/11382843/Son-challenges-Belgian-law-after-mothers-mercy-killing.html

[18] " Normalization " of Euthanasia in Canada : the Cautionary Tale Continues p 28 ff https://www.wma.net/wp-content/uploads/2020/05/newwmj_2_2020_WEB.pdf

[19] Willis D, George R. Conscientious objection and physician-assisted suicide: a viable option in the UK? *BMJ Supportive Palliative Care*; 2019; 9: 464-7.

[20] https://apmonline.org/news-events/apm-physician-assisted-dying-web-materials/ https://www.rcplondon.ac.uk/news/rcp-clarifies-its-position-assisted-dying

https://apmonline.org/wp-content/uploads/2019/01/press-release-apm-survey-confirms-opposition-to-physician-assisted-suicide-2.pdf

[21] In Oregon, doctor-shopping for a willing prescriber is evident with one doctor writing 31 prescriptions *Ibid* endnote 13