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Association for Palliative Medicine of Great Britain and Ireland

Key points for consideration relating to the Terminally III Adults (End of Life) Bill – For the debate 19th September

The APM considers the following points of central importance for further consideration of the Terminally III Adults (End of Life) Bill. We speak as healthcare professionals with lived experience working with, and caring for, those with terminal illness.

1. Universal access to specialist palliative care:

Every person with a terminal illness should have access to specialist palliative care for support and management of symptoms. The vast majority of people who die have palliative care needs¹. Up to 1 in 4 of those who could benefit from palliative care input don't receive it in the UK². Even for those under palliative care services, the provision may be inadequate, with night-time care often particularly hard to access³.

Access to palliative care should not depend on geographical location, diagnosis, age, gender, race or any characteristic. We argue that universal access to quality palliative care is needed in order to give people real choice in end-of-life care.

- 1) Commission on Palliative and End-of-Life Care
- 2) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-024-01574-5
- 3) <u>Better End of Life 2024 Research Report. Marie Curie: experiences-at-the-end-of-life-in-england-and-wales</u>

2. Funding for specialist palliative care separate from Assisted Dying:

For the reasons given above, palliative care funding is vital. Assisted dying services must not be funded at the detriment of specialist palliative care. The budgets should be separate. This supports both a fair choice for people wishing for an assisted death and those who wish to continue receiving palliative care. Please see the evidence behind this here

<u>Evidence of Harm – Assessing the Impact of Assisted Dying : Assisted Suicide on Palliative Care (Prof. David Albert Jones)</u>

3. Conscientious objection for organisations and individuals

We agree with the inclusion under Section 31 of the current Act that no individual healthcare professional is obligated to be involved in the provision of assisted dying (with the noted exceptions). We believe this should be extended to include an opt-out mechanism for individual organisations. This includes hospices, nursing homes, and other in-patient care providers who do not wish to provide assisted dying or external clinicians to come into their services and provide assisted dying. Organisations should not be required or expected to participate in the provision of assisted dying at any level. This organisational objection should be without financial penalty, nor should providers of assisted dying be disproportionally financially incentivised such that it disadvantages non-providers.

Please go here to read our full statement on conscientious objection (written prior to some amendments)

https://apmonline.org/wp-content/uploads/APM-Conscientious-Objection FINAL-1.pdf

4. Upfront panel assessment

We support the principle of a multidisciplinary (MDT) Assisted Dying Review Panel (Section 16) however, not positioned at the end of the assessment. Experience demonstrates the need for a multi-disciplinary shared decision-making assessment of the patient for situations of this gravity, as multi-professional working is at the heart of healthcare.

Therefore, we strongly advocate a requirement for the MDT panel to directly assess the person applying for an assisted death to ensure each aspect of the MDT requirements are met. We also propose that if the panel does not have the relevant experience in a particular condition or situation, they should be able to seek advice and patient assessment from the relevant health, legal or social care specialities.

Please read the Royal College of Physicians Statement:

RCP position statement on the Terminally III Adults (End of Life) Bill, 9th May 2025 | RCP

5. Coordinating doctor and independent doctor eligibility

The specification of exactly who will be eligible to work as either a coordinating or independent doctor is not defined. Section 8 (7) and 11 (9) respectively state that this will be covered by later regulations set by the Secretary of State. The Bill needs to ensure that the doctors involved in the assessment process will have sufficient skills and considerable post-registration experience in the specialist area of medicine relevant to the patient's condition. The palliative care training requirements for professionals in other specialities is therefore also required and will have a significant impact on workforce planning within palliative care.

6. A note regarding 'assistance':

The scope of the term 'assistance' needs to be defined more accurately, particularly in section 25 (8) (b). We note this is recommended to be covered within a 'code of practice' within section 39 (1)(e), but we argue it needs to be defined within the Act for the safety of those involved. Practically, if the patient cannot swallow, or move to drink, or vomiting, for example, what degree of assistance is 'assistance', and what is doctor-provided euthanasia?



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For more information

For more detailed information regarding palliative care and important considerations regarding the Bill written for Peers - please see below

The APM Twenty Key Questions for the House of Lords (Here)

The APM Assisted Dying 'Myth Buster' for the House of Lords (Here)

The APM 'What is Palliative Care?' for the House of Lords (Here)

Thank you for reading and considering this complex issue.

Sincerely,
The APM Executive

Dr Suzanne Kite (President) Dr Paul Paes (VP) Dr Natasha Wiggins (Hon Treasurer) Dr Sarah Cox (Past President) and Dr Matthew Doré (Hon Secretary)