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Palliative Medicine
Of Great Britian and Ireland

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Terminally Ill (Adult) Bill Committee Stage Assisted Dying APM Response 24.01.25

Introduction

The Association for Palliative Medicine of Great Britain and Ireland (APM) is one of the world's largest representative bodies of medical/healthcare professionals practicing or interested in Palliative Medicine, with a membership of over 1,400. APM members have considerable and broad experience in caring for people with life-limiting illnesses, including at the end of their lives, in all care settings.

The APM is concerned about the limited time available to consider and create a robust and safe law about such a complex and serious topic.

Multiple surveys of APM members over the past 10 years show the vast majority (around 80% do not support legalising Assisted Dying (AD).

Assisted Dying and Palliative Care funding

Section (S) 4 subsection (ss) 4.c and Section 9 ss 2.b.iii set out that registered medical practitioners and the assessing doctor must discuss any available palliative, hospice or other care, including symptom management and psychological support. We know that 25% of people who need palliative care in the UK are not receiving it[1,2] and that access to palliative care is inequitable for some ethnic groups, the socially deprived, by geography and out-of-hours[2]. The APM continues[3,4] to express concern about the inadequate access to palliative care and the impact this has on care and experience.

The APM recommends that there must be nationally agreed statutory, fully commissioned provision of adequate, equitable palliative care which includes symptom management and psychological support.

The APM recommends that any funding for AD is completely separate from funding for palliative and end-of-life care. This will create transparency and prevent AD from diverting resources away from palliative care.

Misperceptions about palliative care

The APM is concerned that the debate around this Bill has included misperceptions about the impact of palliative care and opioid medication on survival, what 'normal' dying looks like, and the choice to reduce suffering through excellent palliative care. The APM urges members of parliament to ensure that they are aware of common misperceptions to ensure that they are not unfairly influencing decision-making now and more widely within society. These include:

i) Opioid use in palliative care

With skilled assessment, review and careful titration of opioids/other pain or symptom control medications, opioid use at the end-of-life does not reduce survival[5]. There are other strong pain medications that can be used for people who are not able to take opioids.

ii) Involvement of palliative care and prognosis

Contrary to fears, evidence suggests that earlier access to palliative care services can improve survival as well as symptom control and quality of life[6].

iii) The experience of dying

Most natural deaths are characterised by the body shutting down, and symptoms are usually predictable and manageable with appropriate assessment and support. Our experience is that whilst distressing deaths do happen, these are the exception and most of the distressing experiences would have been preventable with good multi-speciality care, including palliative care, and adequate care to meet the needs of the patient.

iv) Choice towards the end of life

Good palliative care can reduce suffering towards the end of life and reduce requests for AD. Palliative care supports choice by exploring the goals, benefits and burdens of healthcare interventions in the context of an individual's hopes and preferences. Where the burdens of continued medical treatment outweigh the benefits, this treatment may be stopped, either at the request of a patient with capacity or on a best interests' basis for people who lack capacity for treatment decisions. Advance care planning enables us to make known our wishes for medical treatment in specific future circumstances while we have capacity to do so.

The APM recommends that there is public and professional education about the misperceptions in palliative care, to help ensure people know about relevant factors and services that may help them and to ensure that their capacity to make choices is

not impacted by misinformation or unavailability of services. The Bill should also include an urgent public health campaign to raise awareness and understanding about dying, palliative care services and how to access these.

Training for coordinating and registered doctors

Without adequate training, the APM does not believe that registered and coordinating doctors set out in the Bill will be adequately skilled to discuss palliative care needs and services, the impact of illness and AD on those close to the person requesting AD, nor provide sufficient opportunities to reduce the persons suffering through individualised palliative care.

The APM recommends that in section 19.2.b, S5.3.a and S8.6.a there are specific training requirements for coordinating and authorised registered doctors relating to communication and knowledge about palliative care and local and national services.

Prognosis

Section 2 sets out eligibility for AD based on a definition of 'terminal illness' and, in section 2.b.ii, a prognosis of less than 6 months.

Prognostication for the last 6 months of life is notoriously difficult, highly subjective, and evolves with the development of new disease-modifying treatments. Clinical accuracy in predicting prognosis has been shown to be variable, i.e. in the range of 20-60% for people with advanced cancer[7] and similar for people with progressive neurological conditions[8].

The legal requirement inherent in this Bill, that a clinician confirms that a patient is in the last 6 months of their life, is problematic and yet fundamental to its safety. Any prognostication would be open to clinical and legal challenges. There is no safeguard the APM can see that can mitigate this risk.

NB: While the use of prognosis estimation as a criterion for eligibility is inherently flawed, replacing it with a broader, more subjective criterion like "unbearable suffering" would not offer an acceptable solution.

If this Bill is implemented, the APM recommend that the Bill mandates a detailed monitoring and review process of eligible conditions which should be audited and reported independently by doctors who are not involved in the AD assessments, and with a clear governance process to provide accountability and address any concerns identified.

Coercion and influence

Sections 1.2.b, 7.2.g, 8.2.e and 12.3.h set out that a person should not have been coerced or pressured into making an AD decision. Coercion can be direct or indirect, and specific to the individual or societal. Except with very overt direct coercion, coercion can be very difficult to detect and evidence by anyone including doctors. Subtle and unintended coercion can also occur within a therapeutic relationship between clinicians and patients.

Overt coercion whereby a vulnerable person is being exploited by those close to them does happen. 1 in 6 over 65's has had elder abuse[9] and is a concern for which safeguarding processes apply. However, more insidious societal coercion, or unintended coercion, within society and the care professional-patient relationship are even more challenging.

The APM does not have a solution to safeguarding against this.

Doctors raising the option of AD

In Section 4.2 doctors can suggest AD. Doctors influence decisions made by their patients in conscious and unconscious ways and are themselves shaped by their personal and professional life experiences. A doctor suggesting AD to a patient could deliberately or inadvertently influence the patient's perception of AD as a relevant option or lead them to believe that their dying will otherwise be full of suffering, Alternatively, if the patient clearly rejects AD, they may suspect that other treatments suggested by this doctor are driven by an agenda to shorten their lives or may otherwise result in this. This could lead to patients opting not to engage with palliative care or to the loss of trust in a medical practitioner or in the medical profession at a crucial time in people's lives.

The APM suggests that the Bill restricts conversations about AD to those triggered by the patient. This aspect is very difficult. If doctors are allowed to suggest AD, it risks misinterpretation and undue influence. However, prohibiting such discussions imposes an unprecedented restriction on medical dialogue.

Medications used for AD and quality of dying

Section 20 asserts that the Secretary of State will specify an 'approved substance' which will be used for AD. It is important to highlight the lack of scientific evidence for the effectiveness, failure rates or complications of any 'approved substance' used for AD internationally, as well as the lack of consistency in regimens between and within countries in which AD is legal. This is in stark opposition to the usual practice of approving treatments in the UK, which mandates careful assessment of drugs and their combinations. Unforeseen complications may result in increased suffering, undermining a key driver for this Bill.

If this Bill is implemented, the APM recommend that the Bill mandate a monitoring and review quality of dying by AD, including substance used, adverse events, complications, length of time from administration until death, symptom management and the patient's holistic needs. This must be audited and reported independently by doctors who are not involved in the AD assessments and with a clear governance process to provide accountability and address any concerns identified.

No obligation to provide assistance and conscientious objection

Section 23.1 asserts the right of individual healthcare professionals to not be involved in AD. The APM believes that the ability to make a conscientious objection to participating in assisted dying is essential but the Bill does not outline true conscientious objection. This would include being able to refuse onward referral for AD. Currently, in section 4.5 the doctor 'must' refer when asked.

The APM recognises the importance of organisations also being able to conscientiously object to involvement in AD. This is essential for the organisation and also for healthcare professionals choosing where to work with their conscience.

By not having robust conscientious objection at all levels, the Bill risks imposing harm on health or social care practitioners[10] violating their autonomy and risking an exodus of skilled and valuable health and social care practitioners[11].

The APM recommends that the Bill extend the no-obligation clause to onward referral and to include organisations as well as individuals.

Capacity

A decision to end one's life through AD requires a complex balancing of information. It is very common in late-stage illness for mental and physical capacity to fluctuate, and to be increasingly impaired as a direct result of underlying physical processes, compounded at times by other factors such as fatigue, medication and feeling overwhelmed. There are reports from jurisdictions, such as Australia and Canada, of people pursuing AD who are declining pain and symptom-relieving medications due to fears that these will impair their capacity to complete the necessary legal processes. Over 15 years' experience with the Mental Capacity Act shows that doctors continue to make incorrect assessments of individuals' decision-making capacity.

Section 9 (3) (b) sets out that if there is doubt as to the capacity of the person being assessed, the person should be assessed by a psychiatrist. All of these doctors need awareness of current palliative care measures and services to make a consideration of a person's ability to balance relevant factors, a key component in capacity assessments.

In addition to the factors set out earlier about the need to address information, the APM urges the committee to strengthen the Bill in terms of the necessary skills to assess capacity. This must include that doctors undertaking assessments within this Act have sufficient awareness of current palliative care practice and provision and that assessing capacity as part of serious physical illness is part of their usual scope of practice.

Will AD be a medical treatment?

A crucial question is whether or not assisted death by lethal medication is considered to be a medical treatment. Given that doctors are required to assess eligibility for, prescribe, and be present at the administration of the medication, AD might be considered to be a 'medical treatment'. If this is the case then either assisted dying should be offered to **all** people meeting the eligibility criteria, *or* doctors need to behave differently towards this medical treatment than to all other treatments. Both of these approaches are contrary to all prior medical practice and public expectation, and laden with risks of unintended consequences.

The APM recommends that if AD is implemented in England & Wales it is done outside of 'usual medical practice' and is not regarded as medical treatment.

Proxy Signature by Someone Unfamiliar with the Patient

The Bill permits a proxy to sign declarations on behalf of a patient who is unable to do so themselves, provided the proxy is either of "good standing in the community" or has known the patient for at least two years (Section 15). However, the term "good standing" is undefined, introducing ambiguity and leaving the provision vulnerable to inconsistent interpretation and application. This lack of specificity undermines the robustness of this safeguard, potentially exposing the process to risks of misuse or exploitation.

The APM recommends that it is unsafe to have an undefined proxy signature and that this should be removed.

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