# The Terminally Ill Adults (End of Life) Bill: How Should Lawful Assisted Dying Provision be Established in England and Wales, and at what Cost?

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#### **ABSTRACT**

One crucial issue that has historically received little attention within the assisted dying (AD) debate in the UK is what *model* of state involvement and provision should be implemented if AD becomes lawful. Limited attention has been paid to the question of whether AD should be positioned within existing end-of-life care provision, or whether it should occupy a separate space, with distinct provision. The question of the impact on the NHS became an important point of concern in debates about the Terminally Ill Adults (End of Life) Bill 2024-25. These debates raised questions concerning how lawful AD ought to be established, the financial cost of provision for the service which the Bill states must be free, and how best to safeguard the interests of both patients and healthcare professionals.

We consider the Government's impact assessment, possible resource implications and ethical concerns over establishing a lawful AD service in England and Wales. The implications of a model of AD situated either within or alongside existing end-of-life NHS provision or, alternatively, established as a separate service outside existing end-of-life treatment provision are explored. We examine the key issues, including how assisted dying should be funded, drawing on international experiences of different AD models. Our examination reveals that a clear volume/time/cost paradigm emerges, which must be recognised in planning a lawful AD service that avoids encouraging people towards AD. Whatever model of AD is implemented, maximising choice, safety, sustainability and equity of access are key concerns. Given the current NHS funding crisis, a variety of funding options to supplement state funding should be considered.

#### INTRODUCTION

The Terminally Ill Adults (End of Life) Bill 2024-25 presents the latest and most significantly progressed attempt to legalise assisted dying (AD) in England and Wales. This private member's Bill, introduced by Kim Leadbeater, MP, seeks to allow terminally ill adults with mental capacity to receive medical assistance to end their own life. The Leadbeater Bill is the latest in a series of English attempts to permit AD, and is the most comprehensive to date, with more safeguards and a far more detailed proposal than in previous Bills. Yet almost no detail has been included about the system that would need to be established to provide AD and how this would link into existing health care, for example,

whether it would sit within end-of-life NHS provision or elsewhere. The only instruction is to make the Secretary of State responsible for establishing a service which should be free at the point of access. The amended version of the Bill that has passed to the House of Lords (HL) refers to 'commissioned [Voluntary] AD services'(1) and this might suggest that AD would sit within existing health provision. However, there is concern about the ramifications of situating AD within the NHS,(2) and, importantly, there is a successful precedent for state funded services, such as early medical abortion, which, like AD might be regarded as ethically contentious, being provided largely outside NHS provision.

The arguments surrounding the possible arrangements have been given far less attention in public debates or within the academic literature than other questions about how best to provide a safe yet accessible lawful model, and so this article addresses that deficit. The question of the impact on the NHS and the possible financial cost of lawful assisted dying has been raised in debates in the House of Commons and in recent submissions to the HL Committee established to scrutinise the Leadbeater Bill, including submissions about the arrangements.(3) For example, Professor Nicola Ranger, the Chief Executive of the Royal College of Nursing argued it would be 'heartbreaking' to expect people to access AD services amongst other patients being treated in hospital.(3) Questions concerning how lawful AD ought to be established, the financial cost of provision, and how best to safeguard the interests of both patients and healthcare professionals within the service that is established must be determined before lawful AD becomes practically possible.

With lawful AD on the horizon in England and Wales, and elsewhere in the British Isles (the Isle of Man, probably Jersey and potentially Scotland), considering how best to design and establish a system to organise and provide access to AD is vital. Whilst the financial implications of AD are part of our focus, our purpose is not to dehumanise the subject, or to make the ethically reductive claim that whether AD should be legalised should rest on the matter of costs. However, the financial and workforce implications are key to the sustainability of an AD system and so should not be ignored. The cost impact is also relevant to consideration of how services and care at the end of life are funded from a broad perspective. For example, if AD ultimately saves care costs, the saving might be used to improve end-of-life care. If the reverse is true however, the challenge of funding a safe AD service without reducing resources for existing end-of-life services, and consequently reducing choice about how to die, must be addressed. The fact that palliative care is not fully funded by the state and relies on charitable donations, and is not universally available, intensifies the challenge of ensuring that people do not turn to AD because they fear that palliative care will not be available or good enough.

We begin by exploring the impact and possible costs of establishing an AD service by examining the Impact Assessment published by the Department of Health and Social Care in May 2025, and evidence from other jurisdictions. The financial cost is considered alongside some uncertain and contentious

projections about the potential for cost saving from unutilised medical/social care costs and benefits. While predictions are wildly uncertain, we suggest that given that most people actually having an AD will be close to the end of their natural life, the need to provide good end-of-life care and holistic support for the dying may be only minimally diminished by lawful AD. Moreover, besides the ethical arguments about the need to optimise choice at the end of life and to avoid herding people towards AD, the imperative to provide better end-of-life care may also, we suggest, be supported by the economic case. This is because improvements in palliative care should deter some people (who might otherwise be motivated by fear that end-of-life care will be inadequate), from seeking AD and thus beginning the expensive and resource intensive application process.

We then consider the possible arrangements for the AD service and the impact of different models: first, one in which AD would be wholly state funded, either situated within and fully integrated into existing NHS provision, or alongside and semi-integrated into NHS provision. Second, a partially state funded model positioned outside NHS provision and supplemented through charity funding. In so doing, we reflect on sustainability concerns and potential ethically troubling repercussions if AD in England and Wales remains inaccessible to some because of insufficient funds to meet demand.

## THE COST AND IMPACT OF THE AD SERVICE

The possibility that lawful AD would lead to cost saving in the care of very ill, disabled and elderly people has been raised by both opponents and proponents of AD as an important factor. Arguing against AD, it has been suggested that the care costs saved might encourage access to AD, whilst in support of AD, the argument that saved care costs could be used to improve healthcare has been made.(4)

In the period leading up to the second reading of the Leadbeater Bill on 29 November 2024, arguments concerning the impact on existing services and the financial cost of lawful AD intensified. The question of whether lawful AD would be cost-saving or conversely cost-generating, due to the significant administrative and medical professional oversight needed, raises uncertain and conflicting responses. For example, Health Minister, Wes Streeting, has suggested that the cost may either be significant – leeching resources from existing services – or alternatively, that the cost saving from AD would create a dangerous allure:

'There would be resources implications for doing it. And those choices would come at the expense of other choices... You do touch on the slippery slope argument, which is the potential for cost savings if people choose to opt for assisted dying rather than stay in the care of the care providers or the NHS.'(5)

Because clause 41(5) of the Leadbeater Bill mandates that accessing lawful AD must be free at the point of service, the intention is clearly for the state to cover the cost, and so assessing the possible cost and comparing it to the possible costs saved is important.

The usual method of assessing the cost and benefit of a medical treatment, such as a cancer drug, measures Quality-Adjusted Life Years (QALYs), which involves quantifying the potential for a treatment to improve and lengthen a person's life. QALYs assessments are predicated on a consensus that one year of good health is more beneficial than a shorter period of good health, or poor health or death, although we recognise that this is more complex at the end of life.(6) For obvious reasons, this approach is inappropriate when assessing AD. The benefits of and justification for AD are identified as promoting 'personal choice' over the manner of death for terminally ill adults, and so the potential benefit of AD is highly subjective and thus, defies quantification. With no clear means to identify (or agree) how important or significant the possible benefits of lawful AD will be for individuals choosing it, therefore, it is only possible to predict how many people might seek AD, and what the resourcing implications and financial costs are likely to be.

While making accurate predictions about the resource implications and financial cost of an AD service with unknown features is difficult, we are able to consider current costs of caring for people in the last year of life, which we can assess against possible costs of an AD service. Useful estimations of the costs of an AD service have been outlined in planning and cost estimates in Scotland and Jersey as part of their work on proposals for lawful AD. Both jurisdictions have comparably similar healthcare costs and administrative costs in terms of paying staff and the cost of the care provided as in England and Wales, albeit that Jersey has a different model to the UK. Further, the government's Impact Assessment for the Leadbeater Bill sets out a very detailed yet cautiously ambiguous collection of estimations concerning how many people might access AD, the potential costs of establishing and running an AD service, and the costs that might be saved across a broad range of services that would otherwise be expended in caring for individuals until natural death.

The Impact Assessment utilises a range of assumptions about key features of any AD service that would be established. While some quantified and some monetised information is included, the report stresses that this is 'for the most part uncertain with wide ranges attached but should allow for some indication of the order of magnitude' (paragraph 3).(7) For example, the estimated saving for 'unutilised healthcare' in the tenth year of lawful AD is predicted to be in the range of £5.84 to £59.6 million (para. 256).(7) This illustrates how very challenging it is to provide a useful indicator of the monetised impact. Moreover, given the very comprehensive, complex assessment using wide ranges of potential impacts and costs, it is not surprising that the Impact Assessment does not reach any firm conclusion of whether

lawful AD would ultimately lead to care and other cost savings, such as pensions. According to the Impact Assessment, however, there seems to be potential for possible cost saving or cost neutrality *if* a significant number of people die by AD, i.e., if the predicted range is at the higher end of the Impact Assessment estimation. The individual costs of training and paying those facilitating AD – mainly doctors but also other healthcare professionals - will obviously be greater if more people choose AD. Note that the Impact Assessment suggests there would be approximately 32 hours work for health care professionals for each person applying, but as Farg has pointed out, evidence from the Australian state of Victoria suggests this is an underestimation.(8) Some of the costs, such as setting up the office of the AD Commissioner, establishing monitoring and public information services, will be incurred regardless of how many people seek AD. The likelihood is that if more people have AD the cost per person of certain aspects of the AD service will be lower, while the health and care costs saved will be greater. The point at which a terminally ill person dies from AD compared to when they would have died naturally is also extremely important; if a person has AD only days before they would have died naturally almost no care costs are saved, and the cost of that AD will have been significant, as the Impact Assessment demonstrates.

The Impact Assessment uses unpublished data compiled by the National Institute of Health and Care Research (NIHR) Policy Research Unit to suggest that the cost per person during the last *six months* of life, including healthcare, social care, social security are £16,500 on average (page 79).(7) It is interesting that this seems high compared to a recent UK wide study which assessed costs in 2022,(9) which suggested that the average cost of caring and supporting (via pensions etc) for an adult in the *last year* of life is approximately £18,020. This difference may be partly explained by inflation – 2022 cost being lower than future costs – but it also further illustrates the difficulty in assessing these costs.

The Bill demands a potentially lengthy process which can only begin once a person is expected to die from their terminal condition within six months, a prognosis that is recognised as being largely guesswork.(10) The process includes medical assessments by two doctors, two formal declarations made by the patient, and final authorisation by a multi-disciplinary panel overseen by a High Court or more senior Judge who will be appointed to the role of AD Commissioner. This process, which is punctuated with two cooling off periods of seven days and fourteen days (or 48 hours if the person has less than a month to live), would be likely to take several weeks if not more. The Impact Assessment suggests that the process would take two months (para 49).(7)

This means it is likely that a person having AD would potentially curtail their natural life by a maximum of four months, assuming that they wish to die as soon as possible rather than waiting for their condition to deteriorate. The impact assessment confirms this and suggests that care would therefore not be required for between one and four months (page 21).(7) Evidence from abroad suggests that even when terminal illness is not a legal requirement, around 75% of people having AD choose to die in the final

month of their (likely) natural life.(11) This suggests that most people would have AD in the final month of natural life rather than four months before natural death. Consequently, we might suggest that the potential for cost saving is likely to be lower than is suggested in the Impact Assessment. However, as we discuss later, there is also a risk that people may be concerned that they will lose mental capacity and the right to die by AD if they delay it, and so some individuals may choose to expedite arrangements to die

We can also observe evidence from jurisdictions in which AD is lawful and, as a more directly relevant comparison, the estimations of the cost of a possible AD service in Jersey and Scotland. A recent review by Isaac, McLachan and Chaar of evidence from lawful jurisdictions suggests that AD leads to significant net healthcare cost reductions.(12) However, as the review authors point out, the reliability of the limited pool of work that has been done on costs is questionable. Whilst recognising the differences between the health care systems in place in Canada and the UK, Trachtenberg and Braden Manns' cost analysis of the direct costs of the implementation of Medical Assistance in Dying (MAID) in Canada in a fee-for-service setting would lead to a 'reduction in health care spending in the range of tens of millions of dollars per year'.(13) Yet under Canadian law, AD can be accessed by those suffering unbearably, which means people might have many years left to live and thus the cost savings will be more significant than in jurisdictions allowing access only for the terminally ill.

In both Scotland and Jersey, the expectation is for the State to meet the cost of AD. In Scotland, a financial memorandum in relation to the Scottish AD Bill posits that the AD service would eventually become cost neutral because the costs of establishing and monitoring AD, together with the staffing costs, would be covered by care cost savings.(14) The policy work from Jersey also predicts cost neutrality.(15) Both costings use evidence from Oregon and Canada, though with distinct methodologies to inform estimations, leading to quite different outcomes. One-off costs of establishing the service in Jersey are estimated to be far higher than in Scotland. However, the Scottish plans appear to place the AD service within existing provision whereas Jersey proposes a distinct service outside existing provision, which looks likely to be more costly. The Scottish prediction suggests that the AD service including set up, public information, monitoring, staffing and drug costs will be in the region of £208,795 to £251,254 in the first year based on 33 people predicted to access AD services, with 25 of those expected to die by AD.(14) Jersey predicts that if 25 people access AD in the first year, the overall cost would be £1096,225 (para. 577).(15) While both jurisdictions have, to a greater or lesser extent, health systems that are separate and independent to the English health service, staffing and administrative costs across the UK and Jersey (and other Crown Dependencies) are not sufficiently different to explain the gulf between these estimations.

A further important issue that has been recognised in the impact assessment concerns the prediction that only approximately 60% (or 3 in 5) of people applying for AD will actually receive help to die. This

means that the support, medical assessments, and possible review panel authorisation will be accessed but there will be no care cost saving associated with dying sooner by AD. Evidence from comparable jurisdictions, such as Oregon,(16) demonstrates this phenomenon, as approximately one third of people completing the application and assessment process to have AD do not die by AD. In Oregon, however, there is no prospective legal authorisation by a panel, so the process is simpler and quicker than would be the case under the Leadbeater Bill, noting that prospective legal authorisation – initially proposed to be carried out by a High Court Judge before the amendment to a multi-disciplinary panel – is a key safeguard that has been crucial to the pathway to legalisation.(17) Consequently, it may be that a larger group beginning the formal process under the English approach will not ultimately receive help to die. This means that, for this group, there would be no care cost saving coupled with additional costs for the AD service.

Reflecting on the developing work about the cost impact, a clear volume/time/care cost paradigm emerges. If more people access AD and more of those having AD die as soon as possible after being given authorisation, the 'unutilised' health and social care cost saving may be significant. Given the lengthy process of the English approach, however, coupled with evidence from lawful jurisdictions concerning the point at which people die, it seems likely that the number of people actually dying by AD will match the lowest estimates of the Impact Assessment. Moreover, many people beginning the assessment process to have AD will not die by AD, perhaps because they are deemed ineligible, or they die naturally before AD is arranged, or because they become too ill/lose mental capacity to consent to AD. Crucially, many may change their mind after initially asking for AD because they are offered palliative interventions which they feel will adequately support them. Evidence from the US shows that a high number of people (46%) who asked for AD subsequently changed their mind when offered palliative interventions.(18) This possibility demands an approach that must ensure safe access to AD while simultaneously striving to provide good end-of-life care and support for all those who might be eligible for AD. Looking at the possible cost in terms of resourcing the AD service, against the likelihood that cost saving through unutilised health and social care will be less significant than has been suggested, improving end-of-life care provision so that fewer people feel the need to seek AD arguably makes financial sense in addition to being ethically desirable. This is because it would potentially reduce the number of people seeking AD and incurring assessment costs on the pathway to AD who might be motivated by fear that they will not be able to access good enough end-of-life care. As the evidence from lawful jurisdictions suggests, some people who seek the option of AD may be diverted from actually having AD if they believe that palliative care will be good enough.

Ultimately, the possible impact and many aspects of the cost of the AD service will depend on the model of provision. Beyond the commitment under the Leadbeater Bill for the State to cover the cost, the Bill is silent on how and where the service will be established. As Farg has pointed out, 'if the safeguards are embedded within NHS healthcare, they may be vulnerable to the effects of resource scarcity.' (page

12).(8) Establishing an AD service within existing provision may be more cost effective than creating entirely separate provision, but the implications of an integrated AD service require careful consideration. It is therefore important that alternative models should be explored to fully consider the risks and benefits, both in terms of financial costs and the more crucial issue of how best to promote safe, ethical access to AD.

# 3. POSSIBLE MODELS OF PROVISION AND KEY ETHICAL QUESTIONS

The ethical and practical implications of an AD model that is: a) funded by the state and either situated within existing end-of-life NHS provision or directly alongside this provision as a distinct service, or alternatively, b) established as a separate service that is only partially state funded and sits wholly *outside* existing NHS provision, are challenging to explore. In this section, we reflect on key possible features and ramifications of each approach from the perspectives of patients and those providing the AD service, and questions of sustainability and equity of access. Whichever model is adopted, funding for end-of-life and palliative care must be ring-fenced from funding for assisted dying, to avoid the harmful interactions that could otherwise occur – such as the costs of AD reducing the overall funding available, thereby leading to worsening end-of-life and palliative care provision.

#### An AD model situated within or alongside existing end-of-life NHS provision

The model adopted in most jurisdictions that have legalised AD other than the US is one in which AD is state funded and integrated within health and care systems.(19) If the AD service is established within existing end-of-life care in the NHS, patients will presumably receive care and assistance to die alongside patients receiving traditional end-of-life care. In considering the implications of this, comparisons with abortion could be helpful. Such a model may be similar to abortion at a later stage in pregnancy where surgical abortion is provided within maternity units, rather than either at an abortion clinic or, in the case of early medical abortion, at home or wherever the patient happens to be when they ingest the abortion pills.(20) We recognise that people who are eligible for AD may be more likely to have accessed healthcare within or adjacent to the healthcare organisations prior to seeking to access AD under this model, in comparison to those having a late term surgical abortion. However, some patients accessing late abortion services will have been assessed and received care in the same hospital prior to the abortion and so there is still a useful analogy here.

Integrating AD within existing healthcare could engender more holistic provision of care, treatment and the potential availability of an assisted death in the final stages of a terminal illness, provided there is an openness to such integration. In the UK, most palliative care doctors are still against changing the law on assisted dying and this reluctance will impact on whether assisted dying can be integrated into all services. Elsewhere, challenges have arisen where palliative care units do not allow any aspect of

AD to occur on their premises. Some people have to leave the unit and meet assessors in a café, or need to be discharged home to have the assisted death.(21) Only one hospice in New Zealand allows assisted dying on its premises and, in some US States, faith based hospices do not permit assisted dying to occur on their premises and also prevent staff from having discussions about assisted dying with their patients.(22) Yet in countries such as Belgium, there is greater integration perhaps due to the length of time the service has been available, but also more doctors willing to provide the service.(23)

There is, moreover, the potential for negatively impacting other people receiving care if AD is organised and provided within existing healthcare. Patients receiving other end-of-life care or care for a terminal illness could potentially be affected if the introduction of AD, along with the necessary staff time, procedures and space (finding a room if the individual is not receiving care at home), consumes resources.(24) Given current demands on the NHS, it is already 'questionable whether high-quality care for people at the end of life can be delivered' and the National Audit for Care at the End of Life has found that 'needs of families [and others who are important to the dying] person continue to be significant area for improvement'.(25) Within a complex system in which end-of-life care is provided by hospitals, hospices, care homes and at home (where GP, hospice at home services and community nurses are likely to play a role), Scobie has emphasised that 'coordination of care is a major concern for people dying and those who care for them'. Adding AD services could thus 'significantly increase existing inequalities in access to care at the end of life', and it is also important to consider potential impacts on minoritised groups in particular, with research in Canada, for example, revealing barriers to accessing both palliative care and AD for such groups.(25, 26)

If AD is to be provided within existing health provision to those who would be eligible, there is also the possibility that other patients who would not otherwise have considered an assisted death might come to see this as the expected option to take when they become eligible. Concerns about the 'burden' perception have been raised repeatedly during parliamentary consideration of the Leadbeater Bill. The word 'burden' and closely associated words in this context appeared 140 times in the House of Commons Public Committee sittings alone.(27) And the availability of AD within end-of-life care could have a damaging impact on culture in hospitals, care homes, hospices and community nursing, especially for those health care workers who are morally opposed to AD.(8) The impact upon health care professionals routinely caring for patients in palliative care requesting an assisted death (and the Canadian experience reveals that most requests for AD are made by people who are receiving palliative care) can be profound,(28) whether they are directly involved in the assisted death or not, and this should not be overlooked. Conflict may also arise between staff, especially when health care professionals feel restricted in how they can speak and act with a patient requesting an assisted death. In some jurisdictions, institutions prevent AD from even being discussed.(22)

Alternatively, AD could still be NHS funded but situated as a distinct service alongside existing health care provision, as planned in Jersey. This could provide a more demedicalised model,(29) by operating externally, but in parallel to existing NHS care. However, medicine would not be removed as the dominant frame of reference, because the system that we are envisaging here is one that retains some key medicalised elements, namely: the assistance of medical and palliative professionals; the drugs required to end life; and the need to obtain a prescription for these drugs. If such a separate AD service is deemed to be the most appropriate approach, as noted above, this could be comparable to early medical abortion services - state funded yet distinct provision outside the NHS, which involves not-for-profit third sector organisations such as the British Pregnancy Advisory Service (BPAS). This could align with the BMA's preference for a separate AD service outside existing care pathways still enabling doctors to assist their own patients if they wished and had undertaken the appropriate training to be involved in the AD service, but 'arranged, and potentially managed, through a different pathway'. The BMA cites the Jersey Assisted Dying Service that would 'coordinate and deploy the professionals' to deliver this service as an exemplar.(30)

If this separate AD service were to have distinct locations, we suggest that there is a real likelihood of protests outside known locations and thus there could be the need for safe access zones to protect patients and those involved in the provision of the service, as has been in place around abortion clinics - a 150 metre boundary - since November 2024. There may also be the need for parallel offences to criminalise influencing a person's decision to access or be involved in AD, obstructing access or facilitation of access to AD services, or causing harassment. (31) Notably, however, in most jurisdictions that permit AD, assisted deaths are in the patient's own home or usual place of residence, such as a care home. If the patient were in hospital or a hospice but unable to be transferred, then the provision could come to them. Yet there are cases in Canada where patients have had to be transferred home against their preference to have the assisted death that they desire, which can only be distressing for patients and their families, and something to avoid if possible. This may be less likely to happen in the UK, as people need to maintain capacity and the capability to self-administer the lethal drugs, unlike in Canada where self-administration is not the only option because euthanasia can potentially occur days or even hours before a natural death even if a person has lost capacity, if they have an agreed waiver of final consent.(32) The need to self-administer the lethal drugs at a point when the person retains mental capacity and the ability to self-administer under the Leadbeater Bill means that people are more likely to complete an assisted death when they are still able to transfer home, but this might not always be the case. Some people will simply not get to that stage because the requirement to self-administer while retaining capacity, as evidenced in Oregon, means that AD becomes impossible. (16)

A major concern for a state-funded model within or alongside the NHS is equity of access. Besides the well-known 'postcode lottery' for IVF provision funded by Integrated Care Boards, again, an analogy can be drawn with abortion provision. In the NHS's 'Vision for Abortion Services' published in 2024

as a response to the pressures facing the sector, the need for improved access to meet demand through 'greater collaboration between the independent sector and the NHS' and 'appropriately funded, financially sustainable services' is highlighted.(33) Similar challenges regarding sustainability and equity of access could arise for AD provision. It is also notable that, back in the late 1960s following the passing of the Abortion Act 1967, it was anticipated abortion provision could be subsumed within existing NHS provision. Yet the reality was that this could not keep up with demand, leading to the development of private abortion provision, with four abortions being carried out privately to every six abortions on the NHS a year after the Abortion Act 1967 came into effect.(34) Whilst we are not suggesting that the numbers of those seeking an assisted death would be comparable to abortion statistics (then or now), we emphasise the broader point that NHS provision may need to be supplemented or predominantly managed by private provision to meet demand. However, the clear learning from this is that the assisted dying services would need to be "appropriately funded" and "financially sustainable".

# A hybrid private/state supported model

A completely private AD model does not seem to be a possibility given the firm commitment to state-funded provision in the Leadbeater Bill. But given the current NHS funding crisis, it is worth considering a hybrid, partially state-funded, partially private model because this would avoid increasing the strain on NHS resources. Although the separate AD service that the BMA advocates would 'not necessarily [be] separate from the NHS',(30) it could be. Indeed, such a model might address concerns over the implications of state-sanctioned assisted dying through the NHS and over the effect on NHS doctors' clinical time and the work that they would otherwise be doing, which feature in the political and public debate, as well as the academic literature.(8)

We can look abroad to help envisage what such a system could look like. The AD systems in Australian states could be construed as hybrid models: governments funded the development of the required systems, the employment of 'care navigators' and pharmacists, the education of clinicians, and the establishment of review boards, following the legalisation of AD. However, although counselling and assessment for AD attract Medicare benefits (Australia's Commonwealth-funded healthcare insurance scheme), Medicare does not subsidise AD and any service directly related to the procedure.(35) Whilst Western Australia has created a state funding scheme and some resources within Queensland's public health system have been allocated to facilitate access to AD, otherwise, patients are privately billed by their doctors who provide AD services unless individual doctors choose to provide their services for free, as we discuss below.(36)

Drawing a parallel with current palliative care provision, one way in which partial state funding of a hybrid model might be supplemented here is through charity funding.(2) Indeed, with only one third of

hospice care being NHS funded, it is already the case that much end-of-life social care and palliative care is paid for privately or supported through charity funding.(37) Charity funding occurs, to a degree, under the Swiss AD model, in which right-to-die organisations provide AD. Whilst those seeking an AD generally need to cover the costs themselves, some right-to-die organisations, such as Dignitas, will reduce membership fees for people living under 'modest economic circumstances' and Exit's membership subscription is low, at 40 Swiss Francs per annum, with no additional charge for AD after three years of membership. (38) If the costs of setting up a separate AD service here were able to be met by state (NHS) funding, but then a debate over whether it was necessary and justifiable to charge for the actual provision of AD was initiated, there may be consideration of a role for charitable support for this service. Could charity funding from UK-based right-to-die organisations contribute to or even cover this charge for those eligible for an assisted death who could not themselves afford to pay to access AD services? The financial evidence suggests that relevant charities may be in a position to provide support. For example, Dignity in Dying, the largest organisation, declared a total income of just under £2.7 million in 2023, with a £649,475 surplus following all expenditure and after tax, and an accumulated reserve of £1.884 million.(39) Its sister charitable organisation, Compassion in Dying received an income of £609,530, with funds totalling £692,297 in 2023.(40) And Humanists UK, a prominent advocate for AD alongside its other campaigning activities, ended the same year with total funds of £3,164,306 and a £260,000 surplus.(41)

A hybrid system under which the provision of AD was undertaken by charity-affiliated medical volunteers, rather than NHS doctors, offering private provision would take the demedicalisation of AD even further. There might be concerns about right to die organisational partisanship in favour of AD provision, but, from the perspective of those members of the medical profession who would not wish to be involved in AD, the charity-led provision of AD could provide reassurance that they would never feel pressure to participate in the provision, an issue recently highlighted by Hardes Dvorak.(42) Moreover, BPAS's performance as a leading abortion care provider demonstrates that effective and compassionate provision is most likely to be provided by a charity that advocates for safe and equitable access to the health service in question. Whilst a recent Nuffield report appears to suggest that patients want their own doctor who they trust to be involved in their AD, where volunteer doctors have taken over this responsibility in Switzerland, there has been a distinct lack of criticism of their service.(43) Families were positive about the care that they received from right-to-die organisations.(43) Ultimately, gaining the assisted death is the paramount concern to patients and families rather than who conducts it.

If the state were to fund the development of the required systems for an AD service and provide regulations stipulating the required training for assistors, and ensure review and oversight via the AD Commissioner and Review Panels as is proposed by the Leadbeater Bill,(see clause 8(7) and sched. 1 and 2|)(1) this could help allay any ethical concerns about the partisan involvement of right-to-die

organisations and their volunteers as assistors. Currently, there is no such oversight in Switzerland. But then there remains, of course, the fundamental challenge of sustainability.

#### Further questions of sustainability and equity of access

Whether the AD model is fully state-funded or part-private (meaning that doctors who assist could be financially recompensed), it would still be necessary to find enough volunteer HCPs to assist. The (amended) Leadbeater Bill - at clause 31 - provides that two doctors must assess patients seeking AD, but that no person is under any duty to participate in the provision of AD.(1) This is in keeping with the BMA's view that, more than a 'standard' conscientious objection clause, there should be a general right to refuse to carry out any activities related to AD that is not 'based on matters of conscience'.(30)

Whilst the BMA survey suggests an estimate of the number of doctors who are willing to actively participate in assisted suicide (36%),(44) this in-principle number is likely to be an overestimation: in practice, evidence from abroad suggests it is likely to be much lower. According to some estimates from Canada, most of more than 5000 assisted deaths were carried out by just 80 individuals, and Preston's research in the Netherlands shows there are levels of opt out – it isn't necessarily an *either/or*.(19, 45) Some doctors will do nothing, some discuss the desire for a hastened death, some assess, some prescribe, and some administer. It is unknown how many are prepared to help at each level. While the parameters of the right not to participate are subject to change, it seems that institutional conscientious objection will not be prohibited: Kim Leadbeater has opined that there is nothing in the Bill to prevent institutions (hospices, for example) from opting out.(46) If they do, even fewer doctors may be available, and if there is no public declaration of such institutional opting-out, this may make identifying willing clinicians difficult for patients.

In Victoria, the Australian state in which AD has been available for the longest period (since the law came into force in 2019), only seven medical practitioners are trained to provide voluntary assisted suicide per 100,000 adults according to Victoria's Voluntary Assisted Dying Review Board latest report. The Board has expressed concern about the ongoing sustainability of the programme.(47) Hunt has noted that many doctors are 'reluctant to charge fees for voluntary assisted dying services' and thus 'much of their work is unremunerated and altruistic... A sustainable voluntary assisted dying service, however, cannot rely on the goodwill of a small number of doctors who risk burnout.'(48) This same altruistic response, attrition in the already limited trained workforce pool, and a lack of appropriate remuneration, is reported in recently published research on AD provision in Western Australia, with the authors emphasising that AD provision is 'resource intensive and can take an emotional toll'. Moreover, the 'lack of remuneration has also led to a two-tiered system for patients: greater access for those who can afford a fee-paying doctor; and less access for those who cannot.'(p.144)(36)

Finally here, we consider two possible repercussions if AD in England and Wales remains inaccessible to some because of the contribution costs that would be required in a hybrid model or, in the case of a fully state-funded model, because of insufficient funds to meet demand. Consider the situation if AD were also to be legalised in Scotland alongside England and Wales, and the provision through NHS Scotland was better than in England and Wales. There might be some terminally ill individuals in England and Wales with a life expectancy beyond 12 months who would be motivated to move to Scotland for a year, to become eligible for an assisted death that they would have a much greater chance of accessing. Notably, this has occurred in other NHS health treatment contexts.(49) For those who are financially able to consider a house move, or perhaps could do so if they were to downsize, this more localised 'AD tourism' might prove more appealing than the option of traveling to Switzerland with the remaining (albeit unlikely) threat of prosecution for their family members on return, notwithstanding the upheaval involved.

In this and other jurisdictions, inadequate healthcare resources to meet demand or high costs for healthcare have led to the advent of crowdfunding for treatment. Examples already exist of individuals based in the UK who have sought crowdfunding for an assisted death (via Dignitas).(50) It is thus plausible to expect that inadequate funding for legal AD could lead to the advent of crowdfunding for an assisted death. There are numerous concerning ethical implications if this were to occur. Families and friends may feel ethically obligated to contribute to loved ones' crowdfunding appeals even if they are morally opposed to AD. There is the surrender of privacy inevitably involved in the public appeal for donations to have an AD. Third parties might see the potential for profit by marketing the best ways to make crowdfunding campaigns effective in exchange for a proportion of donations received if the donations exceed the amount required for the assisted death. Research on crowdfunding in other contexts has revealed the exacerbation of health inequities because of racial biases, for example, in crowdfunding donors, and because those with greater social networks are often more financially better off.(51) Crowdfunding could also influence attitudes towards AD, advancing damaging perceptions of which cases are the most and least 'worthy' of support for AD.

#### **CONCLUSION**

We have explored questions concerning how lawful AD ought to be established, the financial cost of provision for the service and possible care cost savings, and finally, how best to safeguard the interests of both patients and healthcare professionals within any AD service that is established in England and Wales. After assessing the predictions within the Impact Assessment, and those done in Scotland and Jersey - all suggesting that lawful AD, if funded by the State, is likely to become cost-neutral because of the care costs saved - we suggest that there is good reason to question that prediction. Evidence from lawful jurisdictions, together with consideration of the lengthy and costly formal process demanded by

the Leadbeater Bill, indicate that the overall unutilised care costs saved by people opting for AD seem likely to be less significant than has been envisaged. Understanding the cost and resourcing impact will be crucial to avoid unintended consequences flowing from the potential pressure exerted by financial implications. For example, *if*, as seems likely, the volume/time/cost paradigm means that the AD service will become cost-neutral or more cost-saving if more people die from AD as soon as possible after receiving authorisation, understanding that paradigm to avoid unintended consequences - such as prioritising cost saving at the expense of safeguarding - is essential. The evidence also suggests that because many people who undertake all or part of the AD assessment process will not ultimately die by AD, the potential for cost saving in unutilised health and social care is less significant than people might expect. Ensuring better end-of-life care will divert some people from seeking AD if their motivation is fear of inadequate end-of-life care, which would save the cost of the AD process, as well as meeting the crucially important objective to give all terminally ill people genuine choice at the end of life.

From the perspective of the patient seeking AD, we suggest that the main concern is safe and compassionate access that is not mired in bureaucracy, together with choice over where and when they wish to die. Whether the model of AD adopted is within or outside existing healthcare, the main determining factors as to whether these needs are met will be whether a person and their family are: given support to navigate the process; able to access the requisite doctors and drugs needed; and ultimately, assisted to die in an environment in which they are comfortable. Whatever model of AD is implemented, sustainability and equity of access are key concerns. It may well prove necessary to consider alternative funding options to supplement state funding given the current NHS crisis in order to avoid the problematic ethical implications that we have considered.

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