

Written evidence submitted by The All-Party Parliamentary Group on Choice at the End of Life, from Karin Smyth MP and Rt Hon Kit Malthouse MP, Co-Chairs of the Group (ADY0487)

Summary

The APPG on Choice at the End of Life supports the legalisation of assisted dying for terminally ill, mentally competent adults, subject to strict safeguards. In summary, the APPG believes that:

- The legalisation of assisted dying and investment and improvement in palliative care are not mutually exclusive options. Dying people in the UK deserve and must have both options available to them at the end of life. Without the choice of assisted dying, and even with the best possible palliative and end-of-life care, terminally ill people can experience extreme suffering in their final days.
- Evidence from other countries demonstrates that assisted dying laws can be passed that are safe, compassionate and widely supported. We have heard from jurisdictions across the world, similar to our own, that have grasped this nettle and from whom we can learn best practice in crafting a law fit for our constituents.
- Our current law is not just lacking in compassion, it is unsafe. It forces dying people to contemplate impossible decisions and, in a small minority of cases, take drastic actions to control their deaths. This leads to suffering for the terminally ill person, to their friends and family, and to the wider public.
- There is an inequality whereby those people with the means (those with funds over approximately £10,000) are able to travel overseas to access assisted dying, whilst those without the financial means, or the physical ability to travel, are excluded from this option.
- While the Government's neutral position on assisted dying may well be correct, that should not prevent the Government either from informing the debates on assisted dying or from facilitating them in order to ensure that Parliament can come to a decision.

Introduction

The All-Party Parliamentary Group on Choice at the End of Life is a group of MPs and Peers who meet to support the aim of promoting greater patient choice at the end of life, particularly over where, when and how one dies. The APPG's purpose is:

To improve the experience of dying in the UK by promoting and expanding people's choices at the end of life. To promote a change in the law to allow the choice of assisted dying for terminally ill, mentally competent adults.

Since it was established, the APPG has worked proactively and purposefully to gather evidence from a range of experts, nationally and from overseas, on the practice of assisted dying and the impact of the blanket ban in the UK. We focus on lived experience and expert insight on laws in practice rather than speculation.

The evidence submitted below is a brief summary of the information the APPG has gathered from people who have been impacted by the blanket ban on assisted dying. These experiences support our conclusion that the status quo is unjust, unsafe and unacceptable and that government time must necessarily be devoted to addressing this issue in a comprehensive and evidence-based manner.

To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

The legalisation of assisted dying and investment and improvement in palliative care are not mutually exclusive options. The APPG supports greater investment in palliative care alongside the development of a safeguarded assisted dying law. Evidence demonstrates that even with access to the highest quality of palliative care services, some people still suffer and wish to have control over the timing and manner of their death. There is evidence from overseas that palliative care can flourish alongside the introduction of assisted dying legislation.

Addressing the APPG in 2021, Dr Bill Crawley, former GP, practising palliative care lead and experienced palliative care physician, acknowledged that while the majority of people are able to have “what might be termed ‘good’ deaths” with access to palliative care, his own professional experiences have shown him that a significant minority of patients still die without adequate symptom control or pain relief. Dr Crawley said that he had often been asked by patients for more choice at the end of their lives, and that on many occasions he had witnessed suffering beyond the reach of the current options available. This included patients with motor neurone disease experiencing ‘air hunger’ when removing a ventilator in order to hasten death, and cancer patients being strangled by tumours wrapped around their trachea or vomiting faeces due to bowel obstructions. He added that:

“choice at the end of life, to have an assuredly dignified death in skilled hands, is the only way we can be sure that patients do not have to tolerate subjectively intolerable symptoms.”

Professor Sir Paul Cosford, Emeritus Medical Director at Public Health England, who died of lung cancer in April 2021, shared his experiences of living with a terminal illness with the APPG in November 2020 and wrote about assisted dying in the British Medical Journal. He said:

“My biggest fear around dying is the lack of control...The lack of ability, if all becomes too much, to advance the end a little, to take some control in my final days. I might have a diamorphine pump at that time, and the idea of having an extra vial in the fridge for me to use if I need it is appealing. Despite helpful conversations with excellent palliative care specialists, this final element of choice and self-determination seems to evade me.”

What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?

The evidence from overseas, where assisted dying is legal, demonstrates that legislation which balances individual autonomy and the protection of vulnerable people is both possible and far preferable to the status quo

Assisted dying, as supported by the APPG, describes the process of prescribing on request, life-ending medication to an individual with mental capacity who is already dying, in order to give them the means to control the manner and timing of their own death. This is the eligibility criteria which underpins the legislative models adopted in 11 US states, all six Australian States and in New Zealand.

The evidence we gathered from parliamentarians and frontline clinicians from these jurisdictions, confirms that such an approach successfully balances the importance of promoting individual autonomy at the end of life while protecting those who may be vulnerable.

The Rt Hon Helen Clark, former Prime Minister of New Zealand, said at an APPG meeting in November 2020:

“The central objective of the End of Life Choice Act is to offer the option of assisted dying to terminally ill New Zealanders who meet the criteria set out in the Act. You cannot access this Act if you have a mental illness. You cannot access this Act if you have a disability alone. You must have a terminal illness which is likely to end your life in the next six months....it is about

enabling people to live better as they are dying – whether or not they choose this option – in addition to easing the deaths of those who do and providing protection to the most vulnerable in our society.”

Dr Catherine Forest M.D., M.P.H., is a clinical associate professor of community and family medicine as well as a public health specialist. In 2021, her spouse, Will Forest, who was terminally ill with motor neurone disease, requested and received the aid-in-dying law Catherine had championed in their home state of California. She explained what the law looks like in practice when she supports patients at the end of life:

“Several times, I have had tough conversations with people who do not qualify. The law requires that patients are terminal with less than six months to live, can take the medication on their own, and have the capacity to make their own medical decision. Therefore, people with diagnoses like Alzheimer’s disease and other dementias do not qualify. I regret that better options aren’t available for these patients. However, I believe that learning from current legally defined conditions is important. We need to make sure no one is coerced or chooses assisted dying when they don’t have the capacity to make the decision for themselves.”

Jill Hennessy was the Minister in charge of Victoria’s Voluntary Assisted Dying Bill. She explained that while the passage of the law in Victoria – the first State in Australia to legislate – was hard-fought, once passed, politicians quickly accepted the new status quo:

“The sky hasn’t fallen in. In fact, the highlight of my day is getting letters from people who have been with their family when their choice has been exercised and where their end of life has been achieved with dignity.”

Time and time again, British citizens have testified to the APPG that the choices at the end of life available to citizens in the US and Australia for example are the same choices they wish to have here. Kit, a woman living with disability and terminal cancer, explained:

“In 2017 I was diagnosed with secondary breast cancer, but since I was born I have also lived with a mobility impairment which makes walking very painful. I know my cancer cannot be cured, but I want to explore every possible treatment to prolong my life. But the further I go, I know the drugs will become less effective and the side effects get worse. Eventually my options will run out. I’ve already had adverse reactions to pain meds like morphine; doctors can’t guarantee they can keep me pain-free. When I reach that stage, I just want the ability to go out as ‘me’. I don’t want to be drugged out of my mind, not knowing what’s going on, or unable to express myself. I don’t want to put my death in someone else’s hands, I want to go on my own terms. It feels unfair that people who don’t have terminal illnesses are deciding things for people who do.”

She concluded:

“I don’t want to die, but if I have to, then I want to die ‘free’ and I want to die ‘me’.”

Dr Stephen Duckworth OBE, a veteran disability rights campaigner who has been a wheelchair-user for 40 years, highlighted the important distinction that needs to be made between disabled people and those who are terminally ill in debates on assisted dying. In addition to talking about his own strong support for greater end-of-life choice for terminally ill people, which is shared by 86% of [disabled people](#), Dr Duckworth criticised non-disabled opponents who “exploit the experiences of disabled people and the inequalities and fears we endure in our daily lives”, using this “as a smokescreen for their own agenda to block progress on this issue”. He added that:

“There is no hierarchy of rights. Equality for disabled people cannot be addressed by denying dying people the autonomy, choice and control that they want and deserve over their lives.”

What protections could be put in place to protect people from coercion and how effective would these be?

We should be clear that the current law, the blanket ban on assisted dying, does not protect people and leads to unacceptable failings in patient safety. Without a safeguarded alternative, compassionate relatives feel obliged to assist in the deaths of loved ones and there is anecdotal evidence that some caring clinicians intentionally hasten death as a compassionate response to a patient’s request to end their suffering at the end of life under the doctrine of ‘double effect’.

Our outdated law on assisted dying discriminates between those who can and cannot afford an assisted death in Switzerland; criminalises grieving relatives who support their loved ones to exercise control over their deaths; and forces a small but significant number of dying people to end their lives before they are ready in lonely and sometimes violent ways.

Dying people in this country are the biggest victims of the ban and its unequal effects. Financial and logistical challenges make travelling abroad a ‘business class’ option for only a small number of people. In addition to the substantial cost, the process of arranging an assisted death abroad can be extremely difficult and time-consuming, meaning people often need the help of friends and family to make arrangements. Yet providing any assistance is against the law.

Ann Whaley told the APPG how she was investigated by police after an anonymous call alerted social services of her plan to accompany her terminally ill husband Geoffrey, 80, to Dignitas in February 2019.

“Geoffrey had been by my side for over 50 years and I was determined to be by his until the very end. But in supporting his final wish to die with dignity, I became a criminal under British law. It was utterly devastating to think that I might be arrested or that Geoffrey might be stopped from travelling to Dignitas”

The requirement to be physically able to travel to Switzerland to have an assisted death also means people are ending their lives much sooner than they might otherwise choose to. An NHS clinician, speaking anonymously to the APPG in order to protect her loved ones, explained the realities that she has been forced to face in order to have a dignified death:

“I am 45 and until my diagnosis of secondary breast cancer last September I was a senior mental health professional in the NHS. [She died at Dignitas in Nov 2020]. Like many of the people who have succumbed to Covid-19 this year, I am being forced to die in the presence of strangers, in unfamiliar surroundings, without my husband, family or friends to comfort me. In my case, however, it is the result of the antiquated laws on assisted dying in the UK, which have compelled me to travel to a foreign country to die alone.”

The disparity between the choices available to dying people in the UK and those in jurisdictions which offer more meaningful choice at the end of life through a safeguarded assisted dying law was brought home to the APPG by Sher and Joy’s stories. Sher Safran explained:

“In 2017, the year both my parents turned 88 years old, each one of them was diagnosed as terminally ill, and each was given 6 months or fewer to live. Dad Charlie was failing from advanced Parkinson’s and prostate cancer, and mum Francie was declining from advanced coronary disease, heart attacks and small strokes. They lived in Oregon state which 20 years before had passed the death with dignity law. My parents always believed that there should be the choice of peaceful dying wherever possible. The week before they died they had

arranged for all of us in the family to come together and celebrate their life. On April 20th, at 10 am that morning, mum and dad each drank their medicine, and then they laid down together on their bed as they had done for nearly every night for 66 years. And they held hands, and closed their eyes and they fell asleep. My mum passed very peacefully in 15 minutes, and my dad passed very peacefully 45 minutes later. Their death reflected so beautifully the intent and grace of their lives."

Meanwhile, Joy Munns told us about how her mother, Mavis Eccleston, 80, from Staffordshire, was charged with the murder and manslaughter of her husband Dennis, 81, after he ended his own life at home in February 2018 while dying of bowel cancer. Mavis, who had attempted to overdose at the same time, was resuscitated and later charged. A jury unanimously found her not guilty on both counts following a trial at Stafford Crown Court in September 2019. Joy explained:

"My mom would have done anything for her husband, but she had no idea that her actions, motivated purely by love, would land her in the dock. On top of losing Dad, we were terrified we would lose Mom to life in prison. Under an assisted dying law, this would never have happened. Politicians have to face facts – a law is clearly not working if it makes criminals of innocent great-grandmothers."

In 2021 Dignity in Dying published a report, Last Resort, which tells the stories of the dying people who took their own lives in the absence of an assisted dying law. The report estimated that up to 650 terminally ill people take their own lives every year in the UK in the absence of the safe, legal choice of assisted dying. In April 2022, the Office of National Statistics published data, commissioned by the former Secretary of State for Health and Social Care, the Rt Hon Matt Hancock MP, indicating that people with severe and potentially terminal health conditions are more than twice as likely to take their own lives than the general population.

The devastating impact that the current law has on individuals and their families was revealed to the APPG by loved ones left behind. Irene explained to us that:

"My son Gavin was diagnosed with throat cancer in 2014 at just 50 years old. The throat cancer was rapidly advancing, he couldn't swallow anything - we were told that the tumour would grow daily and, in effect, would slowly but surely strangle him. An assisted dying law could have eased so much of his suffering, knowing that when it became too much he could choose to die when and how he wanted. Without this choice, Gavin felt he was out of options. A few days before he died he attempted to end his life at home and was admitted to hospital. But his choices - or lack of choices - remained the same. It is a measure of his desperation that he walked out of the hospital Emergency Department onto a nearby main road and threw himself in the path of a passing lorry. The effect of the manner of Gavin's death on me and my family is ongoing and unforgettable. I feel I failed him and grieve every day. How much easier it would have been for all of us if Gavin had been given the choice of an assisted death. My family and I could now have an image of him of dying peacefully surrounded by those whom he loved and who loved him. We wouldn't have his violent end constantly hanging over us."

Jill Hennessy, the former Victorian Health Minister, told the APPG how the Victorian Government collaborated with eminent specialists, from neurologists to leaders in palliative care, as well as legal experts, in order to ensure protection and clarity through their law and clinical protocols. She said:

"The Victorian laws have been used safely, they've been used compassionately and all of the risks and reasons that people have used as objections, none of those fears, none of the fearmongering that we've seen during the debates on assisted dying has materialised."

Evidence gathered from frontline clinicians such as Dr Catherine Forest and the careful review of the annual reports on assisted dying from US states and Australia have reassured us that legislation offering terminally ill mentally competent adults the option of an assisted death following assessment by two independent clinicians works as intended. People who seek an assisted death are most often aged between 65 and 85, have a 'good education', and are in the vast majority of cases in receipt of palliative care.

We are aware of sensationalist claims made in the media regarding laws in other jurisdictions, though note the limitations of these stories given that they cannot include clinicians' perspectives due to patient confidentiality.

In this country, clinicians already assess their patients' life expectancy, their decision-making capacity and detect signs of coercion as part of end-of-life care, for example in the withdrawal of life-sustaining treatments like artificial ventilation. The oversight and reporting systems in place for assisted dying laws are much more rigorous than any other clinical practice at the end of life. If Parliamentarians in Australia, New Zealand and the USA are able to develop, implement and monitor assisted dying laws which balance protection and autonomy, we can too.

What should the Government's role be in relation to the debate?

There is a clear role for Government in exploring and publishing data on the experiences of dying people under the existing law on assisted dying. This is not inconsistent with the Government's position of neutrality on the legalisation of assisted dying; it merely informs both the public and Parliament to ensure that debates are as well-informed as possible.

The then Secretary of State for Health and Social Care, Rt Hon Matt Hancock MP, spoke to the APPG in April 2021. He confirmed at the meeting that he had requested the Office of National Statistics to produce data on the numbers of suicides by terminally ill people in 2021. He said:

"Anyone who believes in high quality public discourse would want to see an independent and impartial set of facts on which we can then have a discussion."

He went on to say that, as Health Secretary, he had

"...a role in ensuring that the discussion and debate are as high quality as possible."

We also heard from supporters of Dignity in Dying's Compassion is Not a Crime campaign who called on former Justice Secretary David Gauke to launch an inquiry into the impact of the current law back in 2019. David Gauke explained in January 2023 that he had agreed that the Ministry of Justice would launch a call for evidence on "the positive and negative impacts of the encouraging and assisting suicide offence under the Suicide Act 1961, and of any potential amendment to the law on assisted suicide". In an article in the New Statesman Gauke said:

"There were limits to what I could do as justice secretary but it was obvious, even then, that parliament would one day return to the subject (the Commons had rejected reform in 2015) and my intention was to ensure that the debate was as informed as possible."

He went on to say:

"The previous parliamentary debates on this topic had focused on the efficacy of safeguards to ensure that improper pressure was not placed on those terminally ill to end their lives prematurely. Protecting the vulnerable must be central in determining the law in this area but we should not assume that the current law is safe and humane. Leaving matters as they

are is a choice, just as much as voting for change. For this reason, I wanted to provide an opportunity for people to come forward with evidence on how the law works.”

There is therefore clearly a role for Government in collecting data to inform the debate. We would encourage the Committee to recommend that the Government assists in informing the debate on assisted dying as much as possible, as there is still much unknown about the extent to which dying people take the law into their own hands, the number of dying people who travel overseas to die, and the extent of suffering in the final days of life in various care settings.

We also argue that there must also be a role for Government in facilitating the debate on assisted dying. That is not to suggest that the Government must necessarily abandon its position of neutrality, but it could maintain its position and still ensure that Parliament can thoroughly debate the issue.

In Australia, laws have been passed by equivalent systems to our own by a mix of private members' initiatives and State Government bills. Jill Hennessy described for us the process by which the Victorian Parliament investigated the question of assisted dying thoroughly, leading to an informed debate and, in the end, the adoption of assisted dying into the Victorian Government's legislative programme:

“The Parliamentary Committee had made some recommendations and we used the resources of government to help develop the model. We took those recommendations and we established a panel of eminent people in the medical and legal world. With the use of the experts, we were able to, with political consensus, work through each of these issues and we developed our model of assisted dying.

Hennessy highlighted the evidence that the Committee was able to draw on to inform the debate, which has not yet been highlighted in previous discussions on assisted dying in this country:

“We should never let our political leaders get away with saying that the status quo is acceptable. When people are engaged in a debate about the reasons not to embrace law reform, they must engage in why the status quo is unacceptable. An important part of the debate in Australia was evidence from the coroner about these tragic stories. Evidence from our judiciary who were having to preside and prosecutors who were having to look at these cases they didn't want to prosecute. Nurses who were working in an unregulated area with some patients having the privileged access to terminal sedation while others did not. Others had to die lonely private deaths, with paramedics and police officers discovering them. Others who were given no legal choice, made a choice of their own. We've got to continue to highlight the complete unacceptability of the status quo. But we must build models of assisted dying that have the backing of expertise.”

Hennessy concluded that piloting the assisted dying legislation through the Victorian Parliament:

“...was definitely the most important thing that I think that I've ever done as a politician.”

Rt Hon Helen Clark, former Prime Minister of New Zealand, told the APPG that, following an extensive consultation period, a law was passed by the New Zealand Parliament. It commanded public support, such that it was subject to a nationwide referendum and was approved by a large margin. She said:

“Having examined the evidence and looked back on my 27.5 years of parliamentary experience, I am confident that enacting this [assisted dying] law is the safe, compassionate and right thing to do.”

The APPG for Choice at the End of Life looks forward to colleagues taking steps towards the legalisation of choice at the end of life. By doing so they will be following the example of other free-thinking, liberal and compassionate democracies around the world. Those countries have shown that assisted dying is safe, fair and compassionate for dying people and offers protection to those who are potentially vulnerable. Our own experiences demonstrate that the blanket ban on assisted dying is no longer fit for purpose, providing neither compassion nor protection. We urge the Committee to speak to those most affected by the current law and hear their evidence first-hand on why the law must change.

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