Right to Palliative Care (Scotland) Bill
Response from Compassion in Dying and Dignity in Dying Scotland

Background

Dignity in Dying Scotland is a not-for-profit membership organisation. We believe that assisted dying for terminally ill, mentally competent adults should be legal in the UK and that it should sit alongside high quality and well resourced person-centred palliative care, including hospice care.

Our campaign is informed by the experiences of dying people and their loved ones and seeks to respect the autonomy of dying people while increasing protections for potentially vulnerable people.

Our response to this consultation includes what we have learned from interviews conducted with terminally ill people and bereaved relatives that have been featured in three published reports: The True Cost, how the UK outsources death to Dignitas (2017); The Inescapable Truth, about dying in Scotland (2019); Last Resort, the hidden truth about how dying people take their own lives in the UK (2021).

We believe that the evidence in these reports supports both the requirement for a Right to Palliative Care (Scotland) Bill and Liam McArthur MSP's Assisted Dying for Terminally Ill Adults (Scotland) Bill.

We have supported other consultations on palliative care such as the Scottish Partnership for Palliative Care's Every Story's Ending; Baroness Finlay's Access to Palliative Care Bill and Bambos Charalambous MP's Terminal Illness (Provision of Palliative Care and Support for Carers) Bill, all of which sought to improve the ways in which palliative care is commissioned and funded. We will continue to support these efforts because we know that dying people want and deserve the very best palliative care alongside the option of an assisted death – they are not mutually exclusive aims.

Consultation questions

1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care? Please explain the reasons for your response, including what you think a right to palliative care should deliver.

√ Strongly agree

Dignity in Dying Scotland welcomes this proposal for improving the quality of and access to palliative care. We have learned from the experiences of our members that people value a sense of control over their care and treatment at the end of life; appreciate the opportunity to think about what matters to them; and are grateful for honest conversations which enable them to make informed decisions about their end-of-life care. In addition to managing symptoms this is what comprehensive, high quality palliative care can offer.

As such Dignity in Dying Scotland will always support initiatives that seek to improve the quality and provision of palliative care. However, this will not negate any of the arguments for assisted dying nor reduce demand for a change in the law. We know that even in specialist palliative care settings suffering cannot be relieved in a small but significant number of cases. Palliative sedation, which involves the careful administration of drugs to render dying people unconscious in order to relieve their symptoms, is not always an acceptable option for patients. The Office of Health Economics conservatively estimates that even if every dying person who needed it had access to the level of care currently provided in hospices, 591 people in Scotland a year would still have no relief of their pain in the final three months of their life. This equates to 11 Scots every week.

Dame Cicely Saunders observed that 'how people die remains in the memory of those who live on', and so can have a huge impact on bereavement.' Yet, the blanket ban on assisted dying makes bereavement more difficult for many family and friends. Interviewees featured in our report, The Inescapable Truth (2019), explained that the manner in which they saw their loved one die has resulted in them suffering symptoms of complex grief.

Interviewees in our report Last Resort (2021) revealed that bereavement following a death of a loved one who ended their own life is compounded because they also witnessed their loved ones suffering prior to their death and/or feared the potential legal implications following their loved one's death. People who have accompanied a loved one overseas for an assisted death (The True Cost 2017) have said that while there is comfort in knowing someone has ended their suffering, grief is made more complicated by the death happening in a foreign country. The threat of prosecution on returning to the UK and being treated as criminals for an act motivated purely by love and compassion meant that traditional bereavement support services were also out of reach to them.

> *"It was absolute hell. I don't think I'll ever get over it. To watch somebody suffering and be absolutely helpless... Everything from the lack of dignity to the pain to the lack of control. I feel awful that that was the way she went." (bereaved daughter)*

Meanwhile, evidence shows that following an assisted death, bereaved family members were more likely to believe that their loved one's choices were honoured and less likely to have regrets about how their loved one died (Ganzini JPSM 2009).

Dying people view the option of assisted dying as a choice that would significantly increase their quality of life. The comfort and reassurance of knowing they would have the means to relieve their suffering and die at a time of their choosing would be considered just as valuable as having access to the best possible palliative care. Data from jurisdictions which have legalised assisted dying and evidence submitted to the Westminster Health and Social Care Select Committee explain that for many people, just the fact that assisted dying is an option has a palliative effect and offers a form of 'insurance' for use if their suffering reached state where it was unbearable.

Jurisdictions that have legalised assisted dying illustrate the close relationship of palliative care and assisted dying. Data from Oregon shows over 90% of people who have had an assisted death in have been enrolled in hospice care. In Victoria, Australia, 81% of people who have accessed assisted dying have engaged with palliative care services. Furthermore, research in the USA has found law change has led to doctors improving their skills in end-of-life pain management and increased their confidence in caring for other dying people. The Oregon Hospice and Palliative Care Association opposed assisted dying prior to the implementation of legislation but it now recognises that 'Oregonians need not choose between hospice and physician-aid in dying. Dying Oregonians can choose both from among the options on the end-of-life continuum of care.'

In written evidence to the Westminster Health and Social Care Select Committee, the Totara hospice in New Zealand – a specialist palliative care provider that also supports people with assisted dying – said:

> *Assisted dying fits with palliative care principles and practices, our service, our culture, our values and philosophy […] We did not believe that the introduction of legal assisted dying had no place in palliative care, nor did we believe that these approaches were in competition or counter ideologies. Both were intervention options in the menu of services for the terminally ill.*

Additionally, there is clear evidence that assisted dying can be a catalyst for increasing investment in palliative care. Australian States, for example, have demonstrated how providing assisted dying as a healthcare option and increasing funding to palliative care services can go hand in hand.

This was confirmed by the Westminster Health and Social Care Select Committee, which concluded in its recent inquiry into assisted dying that:

> *"In the evidence we received we did not see any indications of palliative and end-of-life care deteriorating in quality or provision following the introduction of AD/AS; indeed the introduction of AD/AS has been linked with an improvement in palliative care in several jurisdictions." [para 142]*

Finally, frontline clinicians directly involved in assisted dying service provision see assisted dying as part of comprehensive end-of-life care. Dr Chandana Banerjee from California told the Westminster Inquiry:

> *"The assisted dying law allows me to walk alongside my patients, regardless of the decisions they make at the end of life, and not abandon them when it matters most…. I have absolutely no doubt in my mind that providing comprehensive end-of-life care includes both palliative care and the option of medical aid in dying. It is completely consistent with being a good physician and what medicine is all about"*

For all the above reasons, in addition to fully supporting the proposed right to palliative care, we recommend that:

- all healthcare professionals involved in the provision of end-of-life care are given sufficient training and accurate information around the likelihood of symptoms of suffering associated with the dying process and, where possible, how to manage these symptoms effectively. This should include resources to help healthcare professionals have honest conversations with dying people about the types of symptoms they might experience.

- relevant associations and regulators for healthcare professionals produce up-to-date, national guidance setting out best practice on all end-of-life care options including palliative sedation and the practice of voluntarily stopping eating and drinking. This guidance should be tailored to healthcare professionals and also members of the public, so that dying people and their loved ones have clear and transparent information about what choices are available under the current law and how those choices can be implemented. The guidance should be produced with the input of dying people and bereaved family members who have first-hand experience of these practices.

- assisted dying is legalised in Scotland to give terminally ill, mentally competent adults a further option of escaping or avoiding a period of unbearable suffering at the end of lives

2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?
Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

The expanded definition states that palliative care "intends neither to hasten nor postpone death." We believe that this creates an unnecessary tension between palliative care and assisted dying. This friction is in fact misplaced as supporters of palliative care and advocates of assisted dying share several goals such as increasing people's control over their dying circumstances, increasing autonomy through patient-centred care, maintaining dignity and reaching acceptance about death.

The Victoria Ministerial Advisory Panel on Voluntary Assisted Dying noted that: "Dominant arguments about palliative care and voluntary assisted dying portray them as antithetical and attempts at contemporary connections seem contradictory to the values on which palliative care was founded. Such polarisation causes oppositional arguments.

For example, in relation to intention, palliative care predominantly seeks to provide comfort, whereas voluntary assisted dying seeks to assist death. These arguments neglect that the intentions of both actions are to relieve the suffering for someone who is dying.

In its evidence to the Westminster Inquiry, the Totara hospice in New Zealand noted that "Our belief is that the W.H.O. definition of palliative care should be updated to reflect societal changes across the world as this pertains to Assisted Death. We acknowledge that the spirit or intention of the definition is to promote palliative care as care that accepts death as inevitable and is not a curative paradigm. We do not accept that this statement was intended to prohibit patient choice or prohibit palliative care professionals and services working within societal changes/changes to norms/changes in the law."

As such, we would encourage a more nuanced conversation that puts the needs of dying people at its heart while respecting the individual values of clinicians who may wish to be conscientious objectors or conscientious providers of assisted dying.

3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).
What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness (es)?

√ Strongly agree

A right to palliative care can only be beneficial to all people living in Scotland.

This proposal rightly acknowledges the wider social determinants of health and the health inequalities that result from poverty and marginalisation. It is useful to note that law change on assisted dying similarly shone a light on inequalities. Governments that have implemented safeguarded assisted dying laws recognised that inequalities will not be resolved by reducing choices at the end of life and so committed to enabling people to live well by investing in palliative care services alongside law change on assisted dying.

In its evidence to the Westminster Inquiry, the Equalities and Human Rights Commission noted: "In countries that have legalised assisted dying, some National Human Rights Institutions (NHRIs) have taken the position that such legislation can, in principle, be compatible with human rights principles as long as the legislation takes a rights-based approach and the appropriate conditions and safeguards are in place, particularly to protect the rights of disabled people. We concur with this view."

Our report, Dying in Scotland, A Feminist Issue, found that women want end-of-life culture to change and give them more choice and control at the end of their lives; they want their experiences as carers and as people living with terminal illness to be counted; and they want a safeguarded assisted dying law. As the proposal progresses, we hope that practical plans are put in place to ensure that women's voices are heard and valued.

4. What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented. Please explain the reasons for your response.

Palliative and end-of-life care is not the exclusive domain of palliative care specialists. A range of clinicians such as, GPs, intensivists, geriatricians and district nurses, together with social care professionals as well as voluntary sector organisations contribute immensely to supporting dying people and their loved ones. Maintaining this multi-disciplinary and multi-sectoral approach to all aspects of end-of-life care, from improving death literacy to supporting people with advance care planning and to ensuring the highest quality symptom management at the end of life will be vital for the effective implementation of this proposal. ,.

Currently, there is no publicly available data on end-of-life care which details for example, the number of deaths following the withdrawal or withholding of life sustaining treatment; the implementation of DNACPR decisions or the following of Advance Directives to Refuse Treatment. The absence of this information makes it difficult to assess the extent to which mental capacity legislation and clinical guidance on end-of-life care are being properly implemented; to identify clinical training and supervision needs; and to measure progress towards genuine person-centred care.

While we do not wish to set out a full data set, suffice to say that all efforts to assess the accessibility and quality of palliative care, particularly from the perspective of what matters to dying people, would be welcome. Qualitative information, such as that which was collected through the National Survey of Bereaved People (VOICES) would also be of great value for identifying what needs to improve so that dying people have the death that is right for them. As such, we suggest referring to the recent King's Fund report on Dying Well at Home, which provides valuable recommendations for taking a more nuanced and person-centred approach to monitoring the quality of end-of-life care.

5. Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response

The following is a list of examples demonstrating how jurisdictions which have legalised assisted dying have also increased investment in palliative care.

Jurisdiction	Palliative care investment
Victoria, Australia	In 2017, at the same time that voluntary assisted dying law was passed, the government announced more than $62 million in additional funding to palliative care services over a five year period.
Western Australia	In 2019 the State budget included a $41 million end-of-life choices and palliative care services package. As the Voluntary Assisted Dying Bill progressed to the Upper House, the government announced a further $17.8 million for palliative care projects based on the recommendations of the Joint Select Committee Report on End of Life Choices.
Queensland, Australia	When the law passed in 2021, the Government boosted palliative care funding by $171 million over five years, taking annual investment to $250 million. A Palliative and End-of-Life Care strategy was also developed at the same time which noted that "Separate to palliative care investments, voluntary assisted dying will be available in Queensland from January 2023…Having access to both high-quality palliative care and the option of voluntary assisted dying provides dignity, choice, and care to those who are suffering."

New South Wales, Australia	In 2022, State palliative care received $742m additional funding as a result of voluntary assisted dying legislation. Section 185 of The Act requires the annual report to include information about palliative care spending
Canada	Following law change in 2016, the Federal Budget 2017 invested $6 billion over ten years in federal funding to support palliative care. More than $2.1 Million to improve home-based palliative care was also announced in 2023. A 2023 report by the Canadian Institute for Health Information noted that more people are receiving some form of palliative care compared with 5 years ago and that more people are dying at home with palliative support compared with 5 years ago.
France	In April 2024, alongside its draft assisted dying bill, France announced planned new investment of €1.1 billion for palliative and end-of-life care.
Austria	When Austria passed its assisted dying law, it was reported that - an expansion of hospice and palliative care is planned in parallel and a special fund will be created for that purpose…The federal government will provide 21 million euros in 2021, 36 million in 2023 and 51 million euros by 2024. By 2024, a total of 153 million euros will be available for hospice and palliative care.

Data protection

√ I confirm that I have read and understood the privacy notice (referred to above) to this consultation which explains how my personal data will be used

Contact details

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