Humanist Society Scotland response to the proposed Right to Palliative Care (Scotland) Bill

June 2024

About

Humanist Society Scotland represents over 18,000 members across the country. We exist to promote humanist thought and secularism and to provide ceremonies for Scotland's non-religious community. Our network of over 130 registered celebrants conducts thousands of weddings, funerals, and naming ceremonies for people to celebrate key life events in line with their personal beliefs and values.

We exist as part of a global network of humanist organisations that seek to promote and protect human rights, with particular interests in the right to Freedom of Thought, Conscience, Religion and Belief, and Freedom of Expression. Humanism is a philosophy that champions individual autonomy and the scientific method, and rejects supernatural explanations to life's "big questions."[1] Humanism is recognised as a "belief" for the purposes of human rights and equality law and Humanist Society Scotland is recognised in marriage law in Scotland as a "belief body."

Question 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?

Strongly Agree

Humanist Society Scotland welcomes the opportunity to respond to the consultation on the proposed Right to Palliative Care Bill. As an organisation that has long campaigned to ensure people have autonomy and choice at the end of their lives, we recognise the importance of high-quality, patient-centred palliative care. We are fully supportive of the proposed bill. In line with our support for the UNCRC (Incorporation) (Scotland) Act 2024 and the proposed Human Rights Bill for Scotland, we also welcome initiatives which seek to further embed a human rights-based approach in public service delivery.

While it is widely acknowledged that palliative care cannot alleviate all pain or suffering in every case, it is vital that anyone diagnosed with a terminal illness has access to a choice of

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[1] Religion Media Centre, Factsheet: Humanism, 2022.

palliative support. People should be fully informed of their options, and these must be tailored to their evolving physical, psychological, and social needs from the point of diagnosis. Humanists promote fulfilment in our life because we believe it is the only one we have. As such, we are chiefly concerned with individual wellbeing and the right to personal autonomy at every stage of a person's life.[2] In our view, terminally ill adults must be empowered to make informed decisions about their care and death that are right for them.

We welcome the pragmatic approach taken in the consultation, which sets out a number of legislative options in addition to a standalone bill. The consultation also rightly recognises that introducing a legal right to palliative care would not automatically lead to widened access. Nevertheless, we share the view of the member that placing specific obligations on Scottish ministers and health and social care bodies would provide a renewed opportunity to address the challenges facing the palliative care sector.

Question 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?

We do not have a strong view on this specific issue and would support using the WHO definition as the basis for a legal right to palliative care. We would however suggest defining palliative care as "an approach that empowers patients and supports their individual and bodily autonomy," as part of the overall statutory definition. As humanists, we have long championed the right of individuals to have personal autonomy over their bodies, including matters of medical care and treatment. The right to be in control of one's body and the decisions made about it is a cornerstone concept of humanist philosophy and for humanists in their lives.[3]

Question 3: Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender reassignment, 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)?

We believe that enacting a legal right to palliative care will have a positive impact on a number of protected characteristics. Crucially, the key proposal within this consultation is aimed at ensuring all terminally ill people have choice, autonomy, and agency at the end of their lives.

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[2] Understanding Humanism, Humanism: Five Core Features, 2024.
[3] See Footnote 2.

Faith and Belief

The consultation notes that palliative care can incorporate "emotional, spiritual and psychological support" that seeks to help someone have a good quality of life. In practice, this can take the form of pastoral care provided in institutional, community, and personal settings. This has historically been rooted in Christian tradition.

We have long been concerned that palliative care provision does not adequately meet the spiritual and pastoral support needs of non-religious people. A two-year study by Marie Curie found there was frequently a lack of non-religious pastoral support available via their services[4]. In addition, many participants felt their non-Christian beliefs were a barrier to accessing spiritual and pastoral care.

The language used with regard to spiritual care can also present a barrier to non-religious people. It is a common misconception that spiritual care and chaplaincy is only delivered by religious pastors rather than professional staff. It would be helpful for a comprehensive review of pastoral and spiritual care to ensure that such care understood and more consistently had regard for non-religious views. The review should specifically address the issue of non-inclusive language, in order to ensure that all patients, irrespective of their faith or belief, feel encouraged to take up the support available to them.

We hope that a new right to palliative care will provide an opportunity to develop and expand pastoral care provision, in order that it reflects Scotland's increasingly secular profile and impacts positively on non-religious individuals.

Age

Older people in Scotland are far more likely to receive a terminal diagnosis and require access to palliative care. They are also more likely to experience the adverse effects of poor palliative care provision and would benefit greatly if the proposals were fully realised.

We do not believe that a legal right to palliative care would negatively impact any group.

Question 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.

N/A

Question 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?

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[4] Marie Curie, Improving access to palliative care for people with dementia, learning disabilities and people with different or no religious beliefs, 2018.

As this consultation has coincided with the introduction of Liam McArthur's Assisted Dying for Terminally Ill Adults (Scotland) Bill, we feel it is important to briefly address the interaction between palliative care and assisted dying.

In our view, a holistic, patient-centred palliative care offer for terminally ill adults should work in tandem with the right to an assisted death. These rights are not mutually exclusive and have not worked against each other in practice. Taken together, they ensure that people have full autonomy to make the right decisions about their care and their death. In jurisdictions which have adopted a terminal illness model of assisted dying, it is worth noting that the vast majority of people who make an application do so while accessing palliative care. According to recent figures, this was true for 76% of people in New Zealand, 81% in Victoria, and 85% in Western Australia[5].

Moreover, a recent House of Commons inquiry found that palliative care provision had expanded and improved in many jurisdictions following the legalisation of assisted dying.[6] In contrast, there is very little evidence of palliative care services being adversely affected when people have the option of an assisted death. Writing in the *Journal of Palliative Medicine*, researchers comparing patterns of hospice use in various US states singled out Oregon – where assisted dying has been legal since 1997 – as an example of good practice:

> *It is possible that the Oregon Death with Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care and has thus increased hospice referrals.*[7]

Humanist Society Scotland
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[5] House of Commons Health and Social Care Committee, Assisted Dying/Assisted Suicide Inquiry Report, 2024.
[6] See Footnote 5.
[7] Shi-Yi Wang et al, Geographic Variation of Hospice Use Patterns at the End of Life, 2015.