Hospice UK consultation response on a proposed Right to Palliative Care (Scotland) Bill

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

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

Key point:
Death is universal yet the stark inequities that people in Scotland face at the end of life are unacceptable. Successive palliative care strategies have failed to deliver an equitable end of life experience and have not had enough teeth to make sufficient progress. A right to palliative care would provide a stronger legislative underpinning that can be built on to drive real change and improve outcomes for people and the wider system.

Over 60,000 people die each year in Scotland and up to 90% of those who die could benefit from palliative care[1]. Yet too many people are missing out on the care they need at the end of life. People with diagnoses other than cancer, those over the age of 85, those that live alone, people from ethnic minority groups, those who identify as LGBTQ+ and those from deprived communities are all less likely to access palliative care. Where you live, particularly if you live in a remote or rural area, impacts the care that you receive and where you are likely to die. For young people living into adulthood with a life-shortening condition, the transition from children's services to adult services can be particularly challenging. Death is a universal experience. It is not acceptable that the care you receive at the end of your life depends on who you are, where you are or why you are ill.

Everyone should have timely access to high quality, seamless palliative care, when and where they need it, where they are treated with respect, dignity and compassion and are fully involved in decisions about their care. There is only one chance to get care right when someone is dying. Care which goes badly at the end of life can have a profound impact on individuals, their family and loved ones, leaving people at crisis point and prolonging and complicating their grief.

Caring for people at the end of life has a significant impact on the health and social care system. Almost one in three patients in hospital are in their last year of life with people typically spending more than a month of their last year of life in hospital, over several admissions. 95% of people in Scotland use NHS unscheduled care services in their last year of life[2]. Demand for palliative care in Scotland is predicted to increase by over 17% over the next 25 years (2023-2048)[1], and the care people need will become more complex. This means the pressure on the health and social care system is set to grow. We need a whole system approach that delivers the outcomes that matter most to people at the end of life

[1] how-many-people-need-palliative-care.pdf (mariecurie.org.uk)
[2] Mason B, Kerssens JJ, Stoddart A, et al. (2020) Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. BMJ Open 2020;10:e041888. doi:10.1136/ bmjopen-2020-041888

while also making the best use of limited resource to meet the growing demand for palliative care across Scotland.

Despite successive palliative care strategies we have not made sufficient progress in key areas such as tackling inequalities at the end of life. We are unable to evidence people's experiences at the end of life or say who is missing out on care in any systematic way. The existing policy landscape has not enabled different parts of the system to work together to effectively meet people's needs at the end of life. A legal right to palliative care would provide a stronger, legislative underpinning to prioritise palliative care nationally and locally, drive improvement and address systemic issues.

Palliative care spans across not just health and social care, but many other areas of policy such as housing, support for carers and access to benefits. Yet because it is overarching, it's not always clear where it 'sits'. A statutory right to palliative care would raise the profile of palliative care and support its links between other areas of policy and practice. Palliative care is delivered by a patchwork of different services, including hospices, hospitals, care homes, GPs, district nursing and social care and the way services are configured and work together varies across Scotland. This means it is even more important to have strong national monitoring and oversight of palliative care, that respects local variation while delivering equity in the outcomes that people experience at the end of life across Scotland.

A legal right to palliative care would help underpin a whole system, population-based approach to meeting people's needs at the end of life and delivering the best outcomes for individuals, families/carers and the wider system. Delivery of the right to palliative care could drive improved collection and use of data so that we can better understand local population need, the pathways people take through services, and whether we are delivering the outcomes and preferences that people say matter most to them at the end of life. A right to palliative care would provide clarity to the public about the care and support they can expect when living with, or caring for someone, with a terminal or life-shortening condition. It could support a greater focus on future care planning, a more integrated approach to early identification and proactive support and assessment, and better communication, continuity and co-ordination of care. By encouraging different agencies to work together to deliver the right to palliative care, it could foster better partnership and multi-disciplinary working, and help ensure palliative care is factored into long-term workforce planning, training and education. A legislative underpinning to palliative care would clarify responsibilities and lines of accountability and – we would hope - help drive improved resourcing of palliative care to meet growing population need.

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?

Key point:

We support the use of the WHO definition as the legal basis for a right to palliative care. We suggest that this be accompanied by a duty setting out agreed core service provision for palliative and end of life care, and sit within a wider public health approach to palliative care.

Hospice UK supports the use of the WHO definition of palliative care to provide a statutory basis to a right for palliative care. It is likely that there would need to be additional statutory guidance around this definition on what this means in practice and we would also want to see

an accompanying duty setting out agreed core service provision for palliative and end of life care that integration authorities, or their successor organisations, need to commission.

We support the benefits of taking a wider public health approach to palliative care and would want to see what is defined in statute around palliative care, sit in a wider public health approach to palliative care. However we accept that for the purposes of legislation there would need to be a reasonably tight definition of palliative care and the WHO definition would be the most sensible approach.

Communicating the definition of palliative care to the public in a clear, straightforward way and ensuring people know what they can expect from a right to palliative care, is important, especially as we know that there is widespread public misunderstanding of terminology around palliative and end of life care.

3. 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)?

Key point:
With careful consideration, a right to palliative care provides an opportunity to better meet the needs of different groups and people in Scotland who are currently experiencing inequalities at the end of life.

By taking a considered, equity-informed approach, a right to palliative care should help identify, understand and address current inequities in palliative and end of life care. At the moment we have no systematic way of measuring people's experiences of care at the end of life or know how well we are addressing people's needs or who is missing out. A right to palliative care provides an opportunity to have much better data and reporting, and more clearly identify where there are gaps or fragmentation in the current system. A right to palliative care could also require a specific focus on underserved communities, for example identifying the needs and barriers experienced by particular groups; ensuring service design is informed by their views; reporting on the experiences and outcomes of particular groups; and staff training on their needs.

A right to palliative care needs to help narrow inequity, not inadvertently widen it. There would need to be careful consideration to ensure that any unintended consequences of implementing a right to palliative care are mitigated, so that it is not just the people who are most able to claim their right who are able to do so. It is therefore important to focus on the duties that are needed to implement and give effect to the right, not just the right itself. These accompanying duties would need to be implemented carefully, for example, if setting out requirements around an agreed core service provision for palliative and end of life care, as suggested below, we would need to be careful that this didn't drive a 'race to the bottom' or mean a focus on only certain specific things that could inadvertently widen inequity.

The implementation of the right to palliative care needs to consider people of all ages, from babies, children and young people, up to adults and older persons, including the transition period from children's to adult services. The right to palliative care would apply to people living across the whole of Scotland and particular consideration will need to be given to what is needed to support people living in remote, rural and island communities, given the particular challenges these communities face, such as long distances to travel to health care services, poor public transport and infrastructure, and issues around the recruitment and retention of health and care staff. The implementation of the right to palliative care would

need to consider marginalised communities and people who we know currently experience stigma and inequity at the end of life, such as people in prison, those experiencing homelessness, people with addictions, people experiencing socio-economic deprivation, LGBTQ+ people, people from ethnic minorities, people with non-malignant conditions including dementia, and those with learning disabilities.

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.

Key point:

There are a number of provisions that would need to be in place around a right to palliative care in order for it be implemented effectively. These include a duty setting out the agreed core service provision for palliative and end of life care that integration authorities need to commission; defined roles, responsibilities and lines of accountability locally and nationally; improvements in data collection and reporting, particularly of people's experiences of care at the end of life; and improved training, education and workforce planning.

A right on its own is ineffective unless it is implemented and enforceable, and gives leverage to hold those responsible for its delivery to account. While a statutory right to palliative care would provide a legislative touch-point, it is what is put in place around it that will determine how well it is implemented and how likely it will lead to concrete change. We believe that the building blocks that would need to be put in place around a right to palliative care include:

Underpinning duties and lines of accountability

- a duty setting out the agreed core service provision for palliative and end of life care that integration authorities would need to commission and be responsible for delivering. This would be the minimum baseline level of provision and, in addition, integration authorities would need to ensure that the provision of services meets the specific needs of their local population. The provision of services should meet national quality standards and be built around delivering the outcomes that matter to people such as early identification, having a single point of contact/access, prompt assessment, having a single shared care plan and clear communication, continuity and co-ordination of care, and care delivered in a person's preferred place of care and death (respecting that there are nuances and complexities around preferred place of care).
- a requirement for palliative and end of life care to be prioritised and detailed in integration authorities' strategic needs assessments and strategic commissioning plans, with local leadership and local plans setting out how this will be delivered across different agencies. To support this there should be statutory guidance and support for integration authorities on effective strategic planning and commissioning of palliative care.
- defined roles and responsibilities setting out who is responsible for delivering the right to palliative care, with clear lines of accountability from a local to national level. Scottish Government should be responsible for monitoring and reporting on how the right and accompanying duties are being implemented and met across Scotland, and ensuring that the conditions are in place nationally for the right to be delivered locally and equitably across Scotland, including sufficient resourcing and investment. Scottish Government would be ultimately accountable for the right being met across Scotland and Ministerial accountability should include evidenced updates to parliament.

- Integration authorities, or their successors under the National Care Service Bill, would be responsible and accountable for the strategic planning and delivery of services to deliver the right to palliative care locally, in line with agreed core service provision, and ensuring service provision meets the needs of their local population. There would need to be clear lines of accountability that reflect the specific arrangements around children's palliative care. National roles, responsibilities and lines of accountability would need to align and have effect in any new structures that may be introduced via the National Care Service Bill.
- a mechanism for integration authorities to report issues to Ministers where constraints at a national level (e.g. failures of workforce planning, resourcing etc) are preventing or making it difficult for them to deliver on the right to palliative care locally. Ministers should then have to report on and outline the steps they are taking to address the concerns raised. This is similar to the approach in the Health and Care (Staffing) (Scotland) Act 2019.

Data, reporting, monitoring and scrutiny

- requirements for improved collection, measurement and reporting of quantitative and qualitative data on palliative care outcomes and people's experiences of the care they received at the end of life, and clear expectations of how this data would be reviewed and acted on by decision-makers locally and nationally. There is currently no robust, national measurement of experiences of palliative and end of life care. This needs to be addressed. Monitoring of the quality of care should be aligned with the SIGN Scottish Palliative Care Guidelines or equivalent successor guidance. There also needs to be data gathered on people missing out on care and from groups of people that palliative care is not currently reaching. Public Health Scotland should support national and local data collation and reporting.
- improved data sharing and a national platform to share digital care records, to allow care preferences/care plans to be consistently shared, viewed and edited across health and social care services, including the voluntary sector and independent providers.
- requirement for scrutiny by Healthcare Improvement Scotland and the Care Inspectorate of the role of integration authorities in delivering on the right to palliative care and how palliative care is being prioritised and delivered on in strategic commissioning plans.
- a focus on continual improvement i.e. ensuring that implementing the right to palliative care isn't just a tick box exercise but that integration authorities, other agencies and Scottish Government have to provide evidence of how they are continually making progress to improve how they are delivering on implementing a right to palliative care.
- clear communication to the public of what they can expect from a right to palliative care, what this means in practice and how a right to palliative care fits into other legally enforceable rights such as the existing right to health, the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child. If developing specific standards around palliative care, these should be aligned to other standards and outcomes e.g. Health and Social Care Standards and the National Health and Wellbeing Outcomes. The current landscape around standards, rights and outcomes is crowded and confusing, for both the public and professionals, so there would need to be consideration given around how best to align and streamline.

Workforce, education and training

- requirement for training and education in palliative care to be woven into every level of education across the health and social care workforce across all settings, to ensure we have a workforce with the skills and knowledge to identify and support people with palliative care needs, across the system.

- requirement for palliative care to inform long-term workforce planning, in terms of the workforce capacity required to meet the growing population need for palliative care and people's preferences for where that care be delivered, and for this to link across to the Health and Care (Staffing) (Scotland) Act to ensure that there are the right numbers of staff with the right skills in the right place to deliver high quality palliative care across Scotland (both generalist roles and specialist roles)

Resourcing

- The right to palliative care should be underpinned by human-rights budgeting where Scottish Government embeds a rights-based approach into the centre of its budget decisions and those principles ripple down to other decision-making organisations who have responsibility for delivering services. We would want to see the right to palliative care help drive better resourcing of palliative care (including bereavement support) that reflects a population needs based approach and ensures that integration authorities are able to fund the agreed core service provision for palliative care and meet the needs of their local population. Resourcing of palliative care must also include sustainable funding of independent hospice care. We would hope that alongside improved resourcing there would also be improved monitoring and evaluation of palliative care investment, and would like to see a greater focus on this by Audit Scotland along with a recognition that a significant element of palliative care resource spend is from charitable income generated by hospices.
- There could also be learning from the Accounting for Value[3] work carried out in Highland on taking a values based approach that focuses on the outcomes that matter most to people at the end of life while also delivering value/efficient resource use across the system.

Learning from Health and Care Act 2022 in England

The Health and Care Act 2022 introduced a new statutory requirement to commission palliative care in England. However research by Hospice UK and Marie Curie found that only 23 of 42 Integrated Care Boards (ICBs) prioritised adult palliative and end of life care in their Integrated Care Strategy. A recent report by the Westminster All Party Parliamentary Group for Hospice and End of Life Care called for there to be an agreed national minimum standard for the level of provision of palliative and end of life care the ICBs must ensure is provided for and funded[4]. It also called for national quality standards and agreed outcome measures, which commissioners can use to assess the quality of the services they are commissioning.

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.

Key point:

The independent hospice care sector needs to be sustainably funded and their contribution valued if we are to realise the right to palliative care for the people of Scotland.

For a right to palliative care to make a real difference to people, there will need to be a system-wide approach that maximises and values the contribution of all sectors, including the third sector. Independent hospice care providers need to be equal partners. Hospices

[3] Supporting end of life care in NHS Highland - Accounting for Value report (scot.nhs.uk)

[4] APPG Report - Government funding for Hospices HUK.pdf (hukstage-new-bucket.s3.eu-west-2.amazonaws.com)

work in partnership with GPs, district nurses, care homes, hospital teams, social care and other services to support people at all levels of palliative care need, across all settings. They deliver training and education to the wider workforce, provide specialist clinical expertise and support to other services, and are strategic leaders in palliative and end of life care at a local and national level. They support people to stay at home, avoid unnecessary admissions to hospital and facilitate swift discharges.

For independent hospice care providers to be part of the solution they need to be sustainable over the long-term and their staff need to be valued for the vital work they do on a par with NHS staff. To ensure this, the promised new national funding framework for hospice care needs to be developed and implemented properly, including that 50% of hospice care costs will come from statutory funding. In addition, Scottish Government needs to factor in the impact of the hospice sector into future NHS pay awards and ensure there is a mechanism for funding to flow to hospice care providers to allow them to match NHS pay awards for their staff. There needs to be recognition that the principles of ethical commissioning also apply to palliative care and the hospice care sector.

About Hospice UK

Hospice UK is the national champion for hospice care. We represent a community of more than 200 hospices from across the UK, delivering services to adults and children. Our membership includes all of Scotland's independent charitable hospice care providers.

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This response is on behalf of an organisation, Hospice UK.

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