Right to Palliative Care (Scotland) Bill

Photo credit: Margaret Mitchell for Dying in the Margins

A proposal for a Members Bill to give people of all ages living with terminal illness and residing in Scotland a legal right to palliative care.

Consultation by Miles Briggs MSP, Member for Lothian

7 March 2024

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Foreword

The establishment of the National Health Service some 76 years ago and the founding principles of a health service from cradle to grave have underpinned the social fabric of our society.

However, what is often the unrecognised reality is that palliative and end of life care is predominantly provided by the charitable sector in a hospice or hospice at home setting with no legal right to palliative care currently existing. Under current contracts, GPs are obliged to support patients with generalist palliative care, however, for too many people this does not meet their needs, and GP resources are completely overstretched. This situation often has a knock-on effect on how services are planned and funded, the availability of specialist and generalist palliative care workforce including social care, lack of consistent public funding for services traditionally reliant on charity, but, crucially, highlights a need for the wider clinical workforce to be empowered to increase its skills and confidence in this area of practice.

It should also be understood that the many myths surrounding palliative care need to be addressed with a better understanding of the vital support and benefits that palliative care provides to people and their families living with both non-malignant disease and/or cancer at every stage of their illness, and the many different, yet important, challenges which need to be addressed in how care and support is accessed and delivered

Donna's story[1] highlights the scale of unmet palliative care need in Scotland, and its complexities which are increasing rapidly. Donna has experienced multiple hardships throughout her life, financial insecurity being just one. She lives with multiple terminal and chronic conditions, including COPD, is a single parent with caring responsibilities, and has experienced a series of bereavements over the last decade, including the sudden death of her son. Donna's care is not joined up, and she experiences isolation and loneliness from being housebound all the time.

In February 2022 the UK Government accepted a Lords amendment to the Health and Social Care Bill for England (now the Health and Care Act 2022) requiring every part of England to provide specialist palliative care.

The amendment gives statutory force to the commissioning of specialist palliative care by all Integrated Care Boards in England, effectively covering the whole population and working to help end the postcode lottery around equitable access to services in community settings. Before the amendment, research carried out by King's College and supported by Marie Curie had shown that, of 23 Integrated Care Boards with published commissioning strategies, only six had identified end-of-life and palliative care as priorities. Similar concerns have been expressed regarding the status and priority of palliative care services within Integration Authorities in Scotland.

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[1] Donna's story is from Dying in the Margins, a research study by University of Glasgow and Marie Curie exploring the experiences and impact of financial hardship and deprivation for terminally ill people wanting to die at home.

My proposed Bill looks to establish a legal right to palliative care for people of all ages living with terminal illness(es) residing in Scotland and to provide equitable access to the palliative support which is right for them, when and where they need it.

A key question, at the core of this proposal, is, what difference should a right to palliative care make for people like Donna and others across Scotland who are not able to access the support they need to live with terminal illnesses and at the end of their lives.?

There are currently many debates progressing in Government and Parliament around the development of a National Care Service and a Human Rights Bill, with a Housing Bill also indicated in the Scottish Government's programme. The recent Covid-19 pandemic has laid bare long-standing issues, such as the relative absence of future care planning, acute workforce pressures across health and social care, gaps in access to and delivery of palliative care in care homes and people's own homes, and the need for dignity and communication among dying people, their families and workforces in hospitals.

Scotland's ageing population means that year on year, the number of deaths – and the number of people with palliative care needs – is set to increase. Now is the time, therefore, to make sure that palliative and end of life care provision is core to system design, planning, commissioning and delivery. Rapid improvements to palliative and end of life care support are needed to ensure a better end of life for all. As in England, this includes establishing a legal right to palliative care in Scotland. I am in no doubt that any new statutory duty will not resolve all challenges facing the palliative care sector in Scotland, but it can act as a positive step forward to help transform care, support, funding, and planning to cover people dying or approaching the end of their lives.

I am hugely grateful to Marie Curie and the wider hospice sector in Scotland for the support they have provided in bringing forward the proposal for this Bill and the positive change it can help achieve. As a society I believe we all want to see the end-of-life care sector deliver the best possible outcomes for people who need access to palliative care and support services.

I hope you will engage with my consultation and I look forward to receiving your views.

Miles Briggs
MSP for Lothian Region
March 2024

How the Consultation Process works

This consultation relates to a draft proposal I have lodged as the first stage in the process of introducing a Member's Bill in the Scottish Parliament. The process is governed by Chapter 9, Rule 9.14, of the Parliament's Standing Orders which can be found on the Parliament's website at: Scottish Parliament Standing Orders

At the end of the consultation period, all the responses will be analysed. I then expect to lodge a final proposal in the Parliament along with a summary of those responses. If that final proposal secures the support of at least 18 other MSPs from at least half of the political parties or groups represented in the Parliamentary Bureau, and the Scottish Government does not indicate that it intends to legislate in the area in question, I will then have the right to introduce a Member's Bill. A number of months may be required to finalise the Bill and related documentation. Once introduced, a Member's Bill follows a 3-stage scrutiny process, during which it may be amended or rejected outright. If it is passed at the end of the process, it becomes an Act.

At this stage, therefore, there is no Bill, only a draft proposal for the legislation.

The purpose of this consultation is to provide a range of views on the subject matter of the proposed Bill, highlighting potential problems, suggesting improvements, and generally refining and developing the policy. Consultation, when done well, can play an important part in ensuring that legislation is fit for purpose.

Details on how to respond to this consultation are provided at the end of the document.

Additional copies of this paper can be requested by contacting me at

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Enquiries about obtaining the consultation document in any language other than English or in alternative formats should also be sent to me.

An on-line copy is available on the Scottish Parliament's website https://www.parliament.scot/ under Bills and Laws/Proposals for Bills.

Aim of the Proposed Bill

Background

Scotland should be a place where dying, death and bereavement are talked about openly, people can plan and discuss their care wishes, and everyone affected has the best possible end of life experience which reflects what is most important to them.

Each person's palliative care needs are different, and too many people do not access or receive some or all of the palliative support they need when they need it. This leads to poorer physical and mental health, and financial outcomes for terminally ill people, their families and carers when they should be focusing on the time they have left, not fighting against the system for support they need.

This proposal seeks the public's views on making an explicit law that people of all ages living with terminal illness(es) residing in Scotland would have a legal right to palliative care.

Rights are the basic freedoms which belong to each person from birth until death, including a right to the enjoyment of the highest attainable standard of physical and mental health[2],[3]. Rights apply regardless of race, sex, nationality, ethnicity, language, religion or any other status[4].

Health and social care in Scotland became integrated in 2014 by the Public Bodies (Joint Working) (Scotland) Act 2014. This means Local Authorities and Health Boards (Integration Authorities) are required by law to work together with other partners to prepare a Strategic Plan which sets out how integrated community health and social care services will be delivered across the 32 Local Authority areas[5].

Palliative care is not explicitly stated as a legal requirement of Strategic Plans, but is often considered by Integration Authorities (in most areas) as part of integrated health and social care delivery aligned to the Scottish Palliative Care Guidelines. The levels to which palliative care is included in Strategic Plans varies substantially and is not reflected at all by some Integration Authorities. Many also do not have an aligning palliative care strategy.

This results in significant unmet palliative care needs across local populations, meaning a large proportion of people die without some or all of the palliative support they need, despite the fact 90% of people who die in Scotland each year would benefit from it[6].

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[2] Equality and Human Rights Commission: what are human rights?

[3] International Covenant on Economic, Social and Cultural Rights: Article 12

[4] United Nations: Human Rights

[5] Public Bodies (Joint Working) (Scotland) Act 2014

[6] How many people need palliative care? Marie Curie how-many-people-need-palliative-care.pdf (mariecurie.org.uk)

The policy set out below could be made into a standalone Act specifically with the purpose of creating a legal right to palliative care for people of all ages living with terminal illness(es) residing in Scotland, or could be implemented in the form of amendments to Scottish Government legislation, for example the National Care Service Bill[7], or Human Rights Bill.

The purpose of the policy is to eliminate unmet palliative care need for people of all ages living with terminal illness(es) residing in Scotland by providing equitable access to the palliative support which is right for them.

The detail of the policy, explored further in the section on what the bill will do later in this document, will include:

- A definition of palliative care
- Detail of who would be eligible for such palliative care
- Detail of how the right to palliative care would work in practice (for example what bodies would oversee and ensure the delivery of the right, what data would be collected on how well the right is being implemented in practice and what reporting requirements would fall on these bodies to ensure the effectiveness of the policy implementation could be understood and scrutinised)

The purpose of this consultation is to gauge support for the proposal and gather insight from those with professional expertise of dying, death and bereavement and people with lived experience, to shape the policy, and therefore the detail of the bill, further.

What is palliative care?

Palliative care for children and for adults

Throughout this document, we use ‘palliative care’ with reference to both provision of palliative care to both children and adults. Yet while there are many elements in common between children’s and adults’ palliative care – such as similar approaches to symptom management and the need for care to embrace the whole family – there are also some important differences between the two.

In general, palliative care offers physical, emotional, psychological and practical support to people with any illness they’re likely to die from. For adults, this includes conditions such as dementia, heart, liver or kidney disease, motor neurone disease and advanced cancer.

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[7] The National Care Service (NCS) is a Scottish Government led policy, with a current vision of “everyone having access to high quality social care support across Scotland whenever they might need it”. https://www.gov.scot/policies/social-care/national-care-service/. The general principles and amendments of the National Care Service (Scotland) Bill are scheduled to be decided over the coming years, and the National Care Service itself is expected to be operational by 2029.

Palliative support also includes symptom management and can be offered at any point after a terminal diagnosis. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.

Children's palliative care specifically is described as an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death.

It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life, as well as maximising opportunities in life, for the baby, child or young person and support for the family[8]. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The philosophy of children's palliative care is to promote the best possible quality of life and care for every child with a life-shortening condition and their family. This philosophy extends beyond childhood and includes the support young people need as they prepare for adulthood and settle into adult services, often at times of significant deterioration in health.

Palliative care for children is different from adult palliative care in several important ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood or young adulthood.
- Many of the illnesses are familial, so there may be more than one affected child in the family.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.
- A characteristic of childhood is continuing physiological, emotional and cognitive development. Children's palliative care providers need to understand and be responsive to the impact of a child's physiological development on handling of medications as well as each child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Provision of play for all children is essential and education is a legal entitlement[9].

For both adults and children, end of life care is part of palliative care, and is treatment, care and support for people who are thought to be in the last year of life, though some people may receive end of life care for longer, or only in their last weeks or days.

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[8] From here onwards we use 'child' as shorthand for a baby, child or young person

[9] https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children's-Palliative-Care-Fourth-Edition-5.pdf

Defining palliative care

While there is not a definition of palliative care which is used universally across Scotland, in order to determine which services should be considered as part of the legislation for a right to palliative care, and who should have access, there is a need to define palliative care.

The World Health Organisation defines palliative care as:
“Palliative care is an approach that improves the quality of life of patients (people and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.

Public health palliative care is defined by Dr Julian Abel, Director, Compassionate Communities UK, as:
“Focussing on…positive aspects of illness, not just for the patient but also for the caring network, for communities and for civic society. Health promotion is therefore possible even in the context of death, dying, loss and care giving. Physical health is only one aspect of health.

“Public health palliative care also encompasses prevention, harm reduction and early intervention around the experiences of illness and disease and the social morbidities such as loneliness, job loss, school refusal, stigma and social rejection.”[10]

In addition to health and social care palliative support needs, public health palliative care also responds to the needs and cultures of the societies in which they are being implemented, and thinks about death as a social event which is part of everyone’s life course[11].

Everyone is affected by dying, death and bereavement, including families and carers of terminally ill people. Carers are crucial in ensuring terminally ill people get the day to day support they need, but are often overlooked for support themselves; over half (54%) of carers in Scotland say their physical health has suffered because of their caring role, and over a quarter say their mental health is bad or very bad- a third say they have had thoughts related to self-harm or suicide[12].

This definition of palliative care thinks about “living with” dying, death and bereavement with a good quality of life, rather “suffering from” it, language which is commonly used within society to describe dying, death and bereavement.

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[10] E-Hospice: what is public health palliative care? https://ehospice.com/editorial_posts/what-is-public-health-palliative-care-dr-julian-abel-director-compassionate-communities-uk/

[11] All Ireland Institute of Hospice and Palliative Care: Briefing Paper: Public Health Approaches to Palliative Care https://aiihpc.org/wp-content/uploads/2015/02/Briefing-Paper-Public-Health-Approaches-to-Palliative-Care-Nov-2017.pdf

[12] Carers Scotland: The State of Caring 2023 https://www.carersuk.org/reports/state-of-caring-2023-a-health-and-social-care-crisis-for-carers-in-scotland/

The latter often leads to a lack of engagement with services due to fear or uncertainty about different forms of palliative support, including bereavement, and an association with imminent death.

Early interventions of palliative care in a person's care are proven to improve quality of life, including integration alongside active treatment when appropriate. Early access to palliative care can also result in less aggressive end of life care, lower rates of depression, longer survival and higher satisfaction with care among patients[13].

In 2022-23, almost 315,000 people experienced bereavement in Scotland[14],[15]. Bereavement is a universal experience, which will touch us all, and impact each of us differently. Bereavement is a core aspect of public health palliative care, and the pandemic has not only exacerbated existing challenges around bereavement and complicated grief, it has spotlighted a crucial opportunity to consider how well services are equipped to support people through a bereavement, and what needs to happen to improve support both now and in the future.

Public health palliative care strives to eliminate health inequalities, which are defined as unjust and avoidable differences in people's health across Scotland's population and in specific population groups[16]. For example, people living in the most deprived areas of Scotland will live 24 years fewer than those in the least deprived areas[17].

The fundamental causes of health inequalities are unequal distribution of income power and wealth, which can lead to poverty and marginalisation of specific groups, and poorer health outcomes[18].

> **"What good does it do to treat people and send them back to the conditions which make them sick?"- Sir Michael Marmot[19]**

Wider social determinants of health are often overlooked in the context of dying, death and bereavement, but are central to a good quality of life and end of life experience which reflects what is most important to each individual.

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[13] Ferrell, B R et al (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. Journal of Clinical Oncology, 35 (1

[14] UK Commission on Bereavement Scotland briefing https://bereavementcommission.org.uk/media/tzekjiyy/ukcb-scotland_briefing.pdf

[15] National Records of Scotland Vital Events Reference Tables 2022 https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2022/list-of-data-tables#section6

[16] Public Health Scotland: what are health inequalities? https://www.healthscotland.scot/health-inequalities/what-are-health-inequalities

[17] NRS

[18] Public Health Scotland: what are health inequalities? https://www.healthscotland.scot/health-inequalities/what-are-health-inequalities

[19] The Health Gap: The Challenge of an Unequal World: the argument; Michael Marmot

Adequate housing, income, access to health services, social inclusion and non-discrimination are some of the social determinants of health which are crucial to positive end of life experience, but which many terminally ill people, their carers and families face significant barriers to receiving.

**The World Health Organisation definition of palliative care is used in the statutory guidance for Integrated Care Boards (ICBs) in England to implement their legal duty to commission palliative care services. Views are particularly welcome on the definition of palliative care in consultation responses.

What palliative support is available currently, and where is palliative care provided?

Palliative care can be provided in different settings, including in hospital, a hospice, care or nursing homes and a person's own home. Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- Managing physical symptoms such as pain
- Emotional, spiritual and psychological support
- Social care, including help with things like washing, dressing or eating
- Physical, emotional, spiritual and financial support for family and friends

In Scotland, much of the care people receive when their health is deteriorating is called generalist palliative care, including social care, provided by health and social care staff to people living in the community, in care homes and hospitals[20].

Specialist palliative care can support people with more complex palliative care needs and is provided by specially trained multi-disciplinary teams who are usually based in a hospice, NHS specialist palliative care unit or acute hospital, but whose expertise should be accessible from any care setting, at any time[21].

Dying, death and bereavement in Scotland

Scotland has an ageing population meaning people are living longer with more complex conditions. By 2040, 10,000 more people will be dying with palliative care needs, an increase of 20 percent[22].

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[20] Scottish Partnership for Palliative Care: what is palliative care?

[21] Scottish Partnership for Palliative Care: what is palliative care?

[22] How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi:10.1136/bmjopen-2020-041317

Multiple health conditions are becoming the norm in Scotland, starting earlier in life and rising steeply with age, and will have increased by 80% in the next 15+ years[23]. But many existing health and social care models are still focused on single disease trajectories, resulting in significant unmet palliative care need[24].

The numbers of children in Scotland with palliative care needs is also increasing. According to the latest available figures, there are 40% more children who may die young in Scotland in 2018/19 compared with 2009/10.[25] Because rising prevalence is in part due to children living longer, more children than ever before are living with significant medical complexity. Every week, three children die in Scotland from a life-shortening condition.

Future Care Planning

A Key Information Summary (KIS) is a collection of information about a patient extracted from their GP record and is created for each person, usually by GPs, to inform different people and services about their condition(s) and care[26]. A KIS is used to support the creation of a patient’s Future Care Plan.

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Marie Curie led research shows that 69% of people in Scotland have a Key Information Summary (KIS) in place at the time of death, created on average 10 months before death. Around 80% of people in Scotland with cancer have a KIS which is welcome progress in recent years. However, there needs to be continual progress especially around recording carer information, and improving uptake of KIS for people living with non-cancer terminal conditions. For example, dementia requires unique, intense support and deaths from dementia as the main cause of death will rise by 185% in the next 15+ years[27], but many people living with dementia do not have a Future Care Plan.

A Future Care Plan allows patients and healthcare teams to discuss treatment and care options, as well as preferences of place of care and where a person would prefer to die, and helps identify carers. Having a Future Care Plan in place can reduce the amount of time a person spends in hospital, including reducing the number of unnecessary hospital admissions, reduce the likelihood of having to go to A&E, and make it more likely that a person will die in their place of choice.

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[23] How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi:10.1136/bmjopen-2020-041317

[24] How many people need palliative care? Marie Curie how-many-people-need-palliative-care.pdf (mariecurie.org.uk)

[25] *Children in Scotland requiring Palliative Care (ChiSP) 3*, Public Health Scotland. Sept 2020.

[26] Scottish Clinical Information Management in Practice https://www.scimp.scot.nhs.uk/key-information-summary

[27] How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi:10.1136/bmjopen-2020-041317

Where people will be dying

By 2040, two thirds of people will be dying in community settings; at home, in care homes and in hospices. The Covid-19 pandemic provided insight into what this demand would look like, through a rapid shift into community settings to keep people out of hospitals. Services were not equipped to manage such high demand, and the system has been unable to recover leaving many terminally ill people without some or all of the palliative care they need, and workforces burned out.

Carers

Carers of terminally ill people are central to their day to day care, and are the most important factor in someone being able to die at home or not. There is a chance that 65% of people in the UK will provide care during their adult lives[28], but carers are often overlooked for support themselves because of lack of identification, and as many carers do not self-identify as carers or get picked up by formal services, they miss out on support and benefits they may be eligible for. Carer breakdown is also the most likely factor in a person with a terminal illness being admitted to hospital, hospice or a care home.

Unscheduled care services

Pressure on unscheduled care and out of hours services has significantly increased in recent years. Unscheduled care can be considered unplanned, urgent or emergency care and is care that cannot be planned in advance. This can happen any time, meaning services must be available 24/7.

Rising demand in unscheduled care results in major clinical resource and financial pressures on the Scottish health and social care system, and people in the last year of life are significant users of unscheduled care with nearly 500,000 service contacts across Scotland[29].

Palliative care delivered in community settings, including at home and in care homes, reduces pressure on unscheduled care services, which currently cost the NHS at least £190 million per year (for people in the last year of life)[30].

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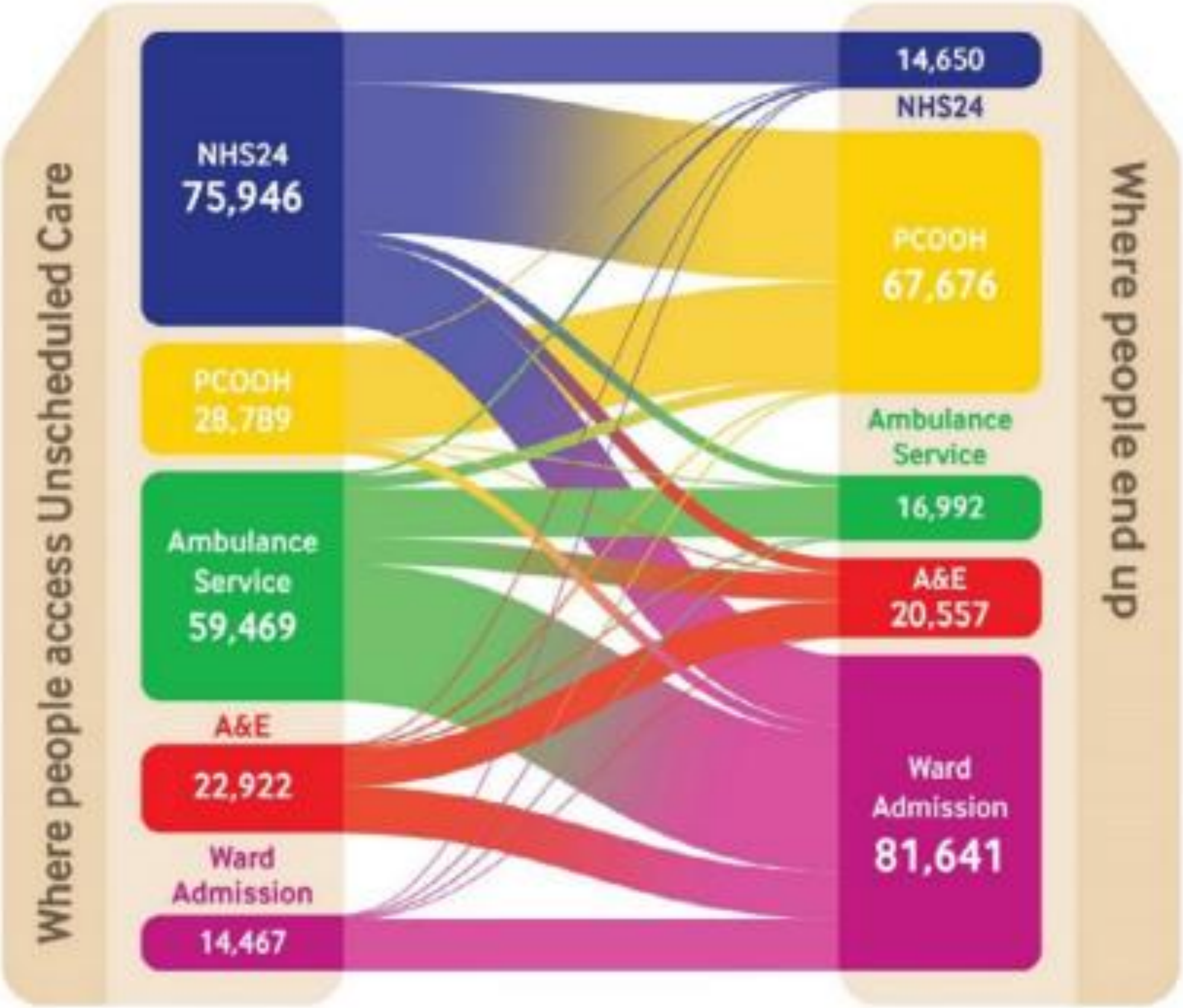
[28] Carers Scotland; carersrightsdaynov19final-2.pdf (carersuk.org)

[29] Mason B, Kerssens JJ,Stoddart A, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. BMJ Open 2020

[30] Mason B, Kerssens JJ,Stoddart A, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. BMJ Open 2020



(*PCOOH is an abbreviation for Palliative Care Out of Hours)

The total cost of unscheduled care used by deprived communities in Scotland is almost double that of the least deprived communities due to large numbers of people dying in these groups, and their higher use of secondary care services.[31]

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[31] Mason B, Kerssens JJ,Stoddart A, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. BMJ Open 2020

Health inequalities and inequities in palliative care

The “Inverse Care Law”, which reflects the people who most need healthcare being least likely to receive it, applies in palliative care as it does in almost every other aspect of life.

In a palliative care context, the “Inverse Care Law” most severely affects people experiencing socio-economic deprivation and financial hardship, older people, women, minoritised ethnicities, LGBTQ+ people, people with learning disabilities and rural and island communities.

We also know the majority of these groups are less likely to ask for help, and this acts as a significant barrier for early identification and engagement with those who would benefit from palliative and end of life care.

Poverty at the end of life affects 8,200 people in Scotland every year, equating to one in four working age people, one in three in areas of acute deprivation, and one in eight pensioners[32].

The greatest increase in demand for palliative care by 2040 will be in people aged over 85, meaning a large proportion of support required will be in rural and island communities who have more elderly populations. But these communities are a forgotten inequity, experiencing unique challenges in palliative care access and delivery:

Availability; of resources for palliative and end of life care providers, including specialist palliative care teams, social care workforce and carers, to meet the needs of terminally ill people.

Accessibility; challenges terminally ill people, their families and carers face accessing palliative and end of life care, including access to medicines pharmacy support. Transportation issues are at the heart of this.

Accommodation; how palliative care providers meet terminally ill people’s preferences and needs. Of greatest concern are existing out of hours of operations, and emergency admissions. Accommodation also relates to the condition of terminally ill people’s own homes, and ensuring they are fit to receive palliative care, and to die there, if that is their wish.

Affordability; of living in rural and island communities. The “rural premium” means those living in rural and remote areas face significantly higher costs in housing, energy and food among others, and is before additional costs associated with terminal illness. Affordability also centres around sustainability of palliative care funding in rural and island communities. Urban centric models are usually transferred, ineffectively, to rural and island communities because they do not reflect population health needs.

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[32] Marie Curie & Loughborough University: Dying in the Poverty at the End of Life

Equity-informed palliative care is often not prioritised for those with the greatest needs at the end of life due to insufficient resources for social care and primary care in areas of high deprivation, those experiencing, or at risk of, financial hardship and those in rural, remote and island communities.

People affected by dying, death and bereavement are often forced to reduce, or give up work entirely because of terminal illness, and when combined with increased costs associated with terminal illness, such as higher energy bills and housing adaptations, leaves people struggling to make ends meet.

The estimated cost of terminal illness in the UK is £12-16,000 per household per year[33], and is unaffordable for many, meaning they die in poverty.

The combination of dying, death and bereavement and poverty often results in isolation and loneliness, which can worsen physical symptoms and impact the mental health of terminally ill people and their carers, leading to poorer health outcomes. It can also lead to complicated grief.

Eliminating inequality and inequity is integral to ensuring a right to palliative care is fulfilled, respected and protected. This will include multiple approaches to physical, emotional and spiritual palliative care, including trauma-informed care.

Misunderstanding palliative care

A lack of knowledge about palliative care options and a reluctance to engage with services are long-standing issues which significantly impact end of life experience.

Dying, death and bereavement remains a taboo subject in the general population as palliative care still carries an association with crisis intervention and/or imminent death. This means the benefits of early engagement are often not fully understood or taken advantage of, or missed altogether.

Which bodies are currently responsible for palliative care delivery?

Sustainability of palliative care delivery and commissioning

Legal responsibility for the strategic commissioning of palliative care in Scotland lies with Integration Authorities, and is managed by 31 Health and Social Care Partnerships.

The organisation and delivery of palliative care is complex and fragmented. Organisations involved in providing palliative care include general practice, care homes, care at home services, hospices, NHS 24, NHS specialist palliative care units, Scottish

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[33] Marie Curie the cost of dying

Ambulance Service, and both acute and community hospitals. In addition to the NHS substantial parts of palliative care are delivered by the Third Sector, the Independent Sector and Local Authorities.[34]

In England, the Health and Care Act 2022 states there is a legal duty on Integrated Care Boards (ICBs) to commission palliative care services[35]:

“An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility.

“Such other services or facilities for palliative care as the board considers are appropriate as part of the health service.”

However, ICBs are experiencing significant challenges in responding to this legal duty[36] relating to:

- **Lack of a consistent strategic focus on palliative care services.** More than a quarter of ICBs said their Integrated Care Strategy does not cover palliative care and almost one in five said their Joint Forward Plan does not do this.
- **Improvements required to fully understand population health need**. While the vast majority of systems (92%) feel they have at least moderately understood the palliative care needs of their population, only 35% of systems report having a significant or full understanding of population health need.
- **Significant gap in understanding and addressing palliative care inequalities.** Understanding and addressing inequalities in access to and experience of palliative care is a major gap for most systems, with two thirds of ICB respondents yet to complete an Equalities and Health Inequalities Impact Assessment, as required in NHS England’s statutory guidance on the new legal duty.
- **Workforce and funding are key barriers to palliative care service improvement.** Workforce and funding issues are considered the most significant barriers to effectively delivering and improving palliative care services. Only 3% of ICB respondents have fully or significantly assessed the required workforce to deliver services effectively.
- **Appetite for additional support to demonstrate the benefits of palliative care investment.** Most systems would welcome additional resources and support to demonstrate the potential value of additional investment in palliative care services.

It is important to be aware of challenges elsewhere to anticipate the support bodies responsible for delivering a right to palliative care will require to meaningfully implement it, and reflect local population palliative care needs.

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[34] Every Story’s Ending: Scottish Partnership for Palliative Care

[35] Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards

[36] In a survey conducted by Marie Curie to explore how ICBs are responding to the Health and Care Act 2022

The third sector plays a key role in existing integrated services but is not seen as an equal partner and is often not included in early conversations with Integration Authorities regarding the strategic planning and commissioning of palliative care services.

Many third sector and independent hospice care providers are commissioned and expected to deliver vital health and social care services to local communities, yet many struggle to secure financial continuity withcrers greater expectation on delivery from statutory partners. There is a recognition and understanding that hospices, hospice care at home providers, and statutory sources will have fewer financial resources in the future, highlighting a need for greater collaborative working and innovation with all key stakeholders to ensure successful outcomes for communities.

The Procurement Reform (Scotland) Act 2014 introduced a sustainable procurement duty on public authorities to improve outcomes for society and reduce inequality. The provisions also remove the obligation to award contracts through competition[37].

Ethical commissioning aims to embed ethical standards in the commissioning and procurement process[38], and shift from process to people to understand and respond to local population health challenges, improving health outcomes. A recent event by Glasgow Council for the Voluntary Sector highlighted that achieving an ethical commissioning approach would require the following principles[39]:

- Changing the mindset of commissioning from process to people
- A fundamental commitment to collaboration and reciprocity
- Build on what good practice already exists
- Delivering locally – Saving money by doing the right thing – Local by default
- Acknowledge the need to invest time and effort in building trusted relationships across system stakeholders and in having challenging conversations
- Being truthful about the constraints (financial, legal, capacity and demand pressures)
- Where possible, radically reduce competition in favour of collaborative approaches
- Reducing bureaucracy and work within 'just enough' structures

Demand for palliative care is growing rapidly, and will have increased by 20% by 2040, at a time when resources from commissioned income are declining continuing a

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[37] SPICE: what is ethical commissioning and why does it matter?
[38] SPICE: what is ethical commissioning and why does it matter?
[39] GCVS: Ethical commissioning and alternatives to traditional procurement

significant proportion of unmet palliative care needs[40]. The financial sustainability of palliative care is paramount in ensuring a right to palliative care in Scotland, and an end of life experience which reflects what is most important to each individual.

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[40] How many people need palliative care? Updated palliative care need estimates 2017-2021: Marie Curie [how-many-people-need-palliative-care.pdf (mariecurie.org.uk)]

Detail of the Proposed Bill

Policy intent of legislation to create a right to palliative care

The detail of the policy in the bill is set out below with key considerations for those responding to the consultation to consider. This is aligned to the purpose of the policy to eliminate unmet palliative care need for people of all ages living with terminal illness(es) residing in Scotland by providing equitable access to the palliative support which is right for them.

1. **A definition of palliative care** – while a holistic definition of palliative care would be the wider policy intention, for example to also incorporate spiritual and financial needs of the individual and support for their families and carers, it is acknowledged that the specifics of a right to be defined in law may have to be narrower than the overarching policy intention. On that basis it may focus on the mental and physical needs of the individual living with terminal illness(es) as defined by the World Health Organisation definition of palliative care used in statutory guidance for Integrated Care Boards to implement their duty to commission palliative care services as legislated in the Health and Care Act 2022.

The 2022 Act states that:

> *(1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility….(h)such other services or facilities for palliative care as the board considers are appropriate as part of the health service.*

The statutory guidance[41] states:

> *Palliative care[42] is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening or life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

2. **Who would be eligible to exercise the right to palliative care** – the right could extend to all people permanently residing in Scotland living with terminal illness(es), of any age.

3. **When someone would be eligible to exercise their right** – given the value and positive impact of early access to palliative care on a person's health outcomes, the proposal is that the right would apply from diagnosis of a terminal illness. There is recognition that, for implementation of the right for all to be effective,

there would require to be system improvements in relation to early identification of terminally ill people.

4. **Where someone would be eligible to access their right** – the right would be exercised in any care setting, including a person’s home, care home, hospital or hospice.

5. **How the right could be exercised** – a person would have a right to an initial palliative care needs assessment upon diagnosis, have a right to receive support within an agreed time frame and within an agreed distance of their home, and have the right to seek a second opinion / appeal or a review if the care offered was not sufficient in the individual’s view.

6. **How the right could be implemented by relevant bodies** – responsible delivery bodies (this would be Integration Authorities in existing health and social care infrastructure) would have a duty to comply with the right’s implementation, delivery of its key functions and workforce requirements (at time of drafting the National Care Service bill is being scrutinised by Parliament and may well be subject to significant change through amendment – on that basis the exact infrastructure that will be in place to deliver the right is currently unknown so pinning down the detail on this element of the policy is challenging).

7. **Data to be collated by relevant bodies -** this could involve an overarching duty on Scottish Ministers to collect and publish data on the number of people diagnosed and living with a terminal illness each year, those in receipt of palliative care and how quickly this was offered and implemented, patient experience/if supporting is meeting needs, and those who do not receive some or all of the treatment they were assessed as needing. These are initial examples, the final metrics would be aligned to reflect the detail in points 1-6 above which are still to be confirmed following this consultation.

8. **Monitoring, measurement and reporting to be published and laid before Parliament on how the right is being developed and exercised in practice** – development and implementation of this policy would involve those with lived experience of dying, death and bereavement, including people living with a terminal illness, carers, and bereaved families, throughout the process, alongside all bodies responsible for delivering it to ensure that qualitative as well as quantitative data feeds into the policy's development, viability and implementation. Reporting on the policy’s delivery would also reflect how responsible bodies are implementing the right, if it is meeting individual needs, and any further resources they may require.

Core resource considerations for legislating a right to palliative care

Palliative care services, including generalist and specialist palliative care, and bereavement services, must be able to meet the needs identified in any re-developed or new assessments. Projection of palliative care need, workforce planning and a sustainable funding framework will be vital to ensure the financial security and viability of hospice care and hospice care at home providers, other palliative care providers including social care, and the third sector.

An example of the current pressure on resources and its impacts is that GPs in Scotland are under the current GP contract obliged to support patients with generalist palliative care. However, for too many people this does not meet their needs. GP resources are overstretched, and evidence has shown that socially deprived groups which do engage, have less time in GP appointments. Additionally, people living in more deprived areas and/or experiencing multiple disadvantage are less likely to register and engage with GPs.

Consultation questions

Note: All answers to the questions in this section may be published (unless your response is “not for publication”).

Aim and approach

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
☐ Partially agree
☑ Neutral (neither support nor oppose)
☐ Partially disagree
☐ Fully disagree
☐ Unsure

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

Terminally ill adults and children and young people with life shortening conditions should have a right to high quality, appropriately funded and easily accessible palliative care services. Providing that all palliative care in Scotland reaches these conditions, we agree that there should be a right to palliative care, enshrined in law. We agree with the goal to eliminate unmet need.

However, as the consultation document makes clear, palliative care services across Scotland do not currently meet these conditions. Therefore, legislating to provide a universal right to palliative care is problematic. To address this, any legislation must seek to improve the underlying funding and workforce challenges which exist, in order that palliative care services are strengthened and can be expanded to everyone who needs them.

For example, as the professional body for pharmacists in Scotland, we are aware of vital role that high quality palliative care offers patients, families and carers, particularly in a medicines context. Royal Pharmaceutical Society has partnered with Marie Curie to develop Daffodil Standards for Community Pharmacy, which support community pharmacy teams to provide the very best palliative care across a range of areas including identifying patients who need support, support for carers, co-ordinated care and quality care during the last days of life and after death. Although many community pharmacies have signed up to the standards, the service is not universally accessible. As experts in medicines and accessible in communities on most high streets, including in remote and rural areas, pharmacists have a unique and positive contribution to make to palliative care, yet patients are subject to a postcode lottery which is largely determined by underlying funding and workforce challenges.

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 WHO definition outlines an approach however, this is not easily translated into a list of practical rights to support across the health and social care system. It may be helpful to publish these proposed rights alongside the definition so all stakeholders including Integration Authorities, Boards, healthcare professionals, patients and carers are clear about what they have a legal right to. Otherwise, the WHO definition will be open to interpretation and could lead to the postcode lottery system which this proposed legislation is specifically trying to avoid.

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
   ☐ Partially agree
   ☑ Neutral (neither support nor oppose)
   ☐ Partially disagree
   ☐ Fully disagree
   ☐ Unsure

Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

The consultation document states that the inverse care law applies in palliative care. Community pharmacies are one of the few services that has the potential to buck the inverse care law, with academic literature stating that "community pharmacies offer a key resource for tackling health inequalities".[41]

In our view, community pharmacies are a key resource to provide palliative care services, and the Daffodil Standards for Community Pharmacy which were published last year provide a strong underpinning to this.

Ensuring community pharmacies are adequately resourced to support patients, families and carers palliative care needs will be critical to the success of this initiative. Furthermore, appropriate use of community pharmacy will support everyone, particularly those living in remote and rural areas, to access palliative care services.

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.

One element to consider is when the right to palliative care becomes available for an individual – the consultation paper describes this begins when a diagnosis of a terminal illness is made, however, there will be groups of patients where their long term condition(s) become advanced with a terminal prognosis, but may be less straightforward to recognise for the clinical team providing their care. E.g. frailty

Relevant duties for pharmacy and medicines may include:

- Duty to inform all healthcare professionals involved in the patient's care about the patient's anticipatory care plan; goals of the treatment plan and in the event of their death
    - This could be implemented by a shared digital health record
- Duty to include a pharmacist in multidisciplinary delivery of general or specialist palliative care in any care setting
- Duty to educate patients and their carers on their medicines and anticipated effects

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[41] https://academic.oup.com/ijpp/article/31/6/594/7295322, Viewed on 13/03/2024

- Duty to provide timely access to medicines, including urgent end of life medicines in the out of hours period
- Duty to undertake multidisciplinary workforce planning for general and specialist palliative care delivery

Of note, currently there is no universal and funded out of hours access to medicines. This is often through local goodwill arrangements between Boards and community pharmacies. If the right to palliative care was to be enshrined in law there must be a properly resourced service put in place, addressing the challenges that this may present in remote and rural communities.

The challenges related to accessing palliative care medicines are multifaceted and extend beyond transportation issues (as described in the consultation paper). While transportation can indeed be a barrier, other factors also play a crucial role.

Community pharmacies face increasing challenges in obtaining consistent supplies of medicines. Shortages of essential medications can disrupt patient care and care planning. Recent examples of such shortages include medications like levomepromazine and hyoscine butylbromide injections, commonly used in palliative care, which have experienced short periods of being out of stock in community pharmacies. Such shortages can be challenging for pharmacists to manage and can directly impact patient well-being.

The Royal Pharmaceutical Society is undertaking a project to investigate the causes of medicines shortages and will publish a report including recommendations for addressing the challenges by the end of 2024.

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.

N/a

How to respond to this consultation

You are invited to respond to this consultation by answering the questions in the consultation and by adding any other comments that you consider appropriate.

Format of responses

If possible, please submit your response electronically – preferably in a MS Word document. Please keep formatting of this document to a minimum.

Please make clear whether you are responding as an individual (in a personal capacity) or on behalf of a group or organisation. If you are responding as an individual, you may wish to explain briefly what relevant expertise or experience you have. If you are responding on behalf of an organisation, you may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

Please include with your response contact details (e-mail if possible, or telephone or postal address) so we can contact you if there is any query about your response.

Where to send responses

Responses prepared electronically should be sent by e-mail to:

Miles.Briggs.msp@parliament.scot

Responses prepared in hard copy should be sent by post to:

Miles Briggs MSP
Room M3.10
Scottish Parliament
Edinburgh EH99 1SP

You may also contact Miles Briggs' office by telephone on (0131) 348 5944.

Deadline for responses

All responses should be received no later than **4 June 2024**. Please let me know in advance of this deadline if you anticipate difficulties meeting it.

How responses are handled

To help inform debate on the matters covered by this consultation and in the interests of openness, please be aware that I will publish all responses received (other than "not for publication" responses) on Marie Curie's website What Marie Curie does in Scotland. Published, responses (other than anonymous responses) will include the name of the respondent, but other personal data sent with the response (including signatures, addresses and contact details) will not be published.

Where responses include content considered to be offensive, defamatory or irrelevant, my office may contact you to agree changes to the content, or may edit the content itself and publish a redacted version.

I expect to prepare a summary of responses that I may then lodge with a final proposal (the next stage in the process of securing the right to introduce a Member's Bill). The summary may cite, or quote from, your response (unless it is "not for publication") and may name you as a respondent to the consultation (unless your response is anonymous).

If I lodge a final proposal, I will be obliged to provide copies of responses (other than confidential responses) to the Scottish Parliament's Information Centre (SPICe). SPICe may make responses available to MSPs or staff on request.

Requests for anonymity or for responses not to be published

If you wish your response to be treated as **anonymous,** please state this clearly. You still need to supply your name, but if the response is treated as anonymous, only an anonymised version will be published or provided to SPICe. If you request anonymity, it is your responsibility to ensure that the content of your response does not allow you to be identified.

If you wish your response to be treated as "not for publication" please state this clearly. If the response is treated as confidential it will not be published or provided to SPICe.

Other exceptions to publication

Where a large number of submissions is received, particularly if they are in very similar terms, it may not be practical or appropriate to publish them all individually. One option may be to publish the text only once, together with a list of the names of those making that response.

There may also be legal reasons for not publishing some or all of a response – for example, if it contains irrelevant, offensive or defamatory content. If I think your response contains such content, it may be returned to you with an invitation to provide a justification for the content or to edit or remove it. Alternatively, I may publish it with the content edited or removed, or I may disregard the response and destroy it.

Data Protection

As an MSP, I must comply with the requirements of the General Data Protection Regulation (GDPR) and other data protection legislation which places certain obligations on me when I process personal data. As stated above, I will normally publish your response in full, together with your name, unless you request anonymity or ask for your response not to be published. I will not publish your signature or personal contact information. For this consultation, your response will be published by Marie Curie on their website.

Information on how I process your personal data is set out in my **privacy notice**, which can be found here https://www.milesbriggs.scot/right-to-palliative-care-consultation. Please confirm that you have read the privacy notice by ticking the box below.

✓ 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.

If a respondent is under 12 years of age, I will need contact you to ask your parent or guardian to confirm to us that they are happy for you to send us your views.

☐ Please tick this box if you are under 12 years of age.

I may also edit any part of your response which I think could identify a third party, unless that person has provided consent for me to publish it. If you wish me to publish information that could identify a third party, you should obtain that person’s consent in writing and include it with your submission.

If you consider that your response may raise any other issues under the GDPR or other data protection legislation and wish to discuss this further, please contact me before you submit your response. Further information about data protection can be found at: www.ico.gov.uk.