Guide to the consultation on a proposed right to palliative care in Scotland.

Information for organisations and individuals to support their consultation responses to Miles Briggs MSP's Proposal for a Member's Bill for a Right to Palliative Care.

March 2024

1. About the consultation process

This consultation is the first stage of the process in introducing a Members Bill for a Right to Palliative Care in Scotland, being led by Miles Briggs MSP with cross-party support from Bob Doris MSP and Rhoda Grant MSP.

This consultation focuses on whether there should be a right to palliative care in Scotland, and what it should deliver. It is open to anyone to respond to, even if they are not in Scotland.

Consultations play an important part in ensuring that legislation is fit for purpose. They are designed to provide a range of views, highlighting potential problems, and suggesting improvements.

Your response would be particularly helpful if you are:

- Someone living with a terminal illness and/or caring for someone living with a terminal illness – or you have recent experience of this.
- A professional involved in delivering palliative care or support to terminally ill people, and other health and social care professionals, in any sector..
- Part of an organisation working on issues relevant to how people may experience end of life, including health inequalities and inequities, poverty, carers and bereavement.
- A Human Rights organisation
- Working in research or the academic sector
- A body currently responsible for commissioning palliative care

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- A Royal College or other relevant professional body
- A Trade union representing the workforce who support people with terminal illnesses and at the end of their lives.

The consultation is open until Tuesday 4th June 2024, and you can either send your responses electronically or a hard copy by post. Details of how to submit your response, how your response will be used, and privacy policy can be found **here.**

Why a right to palliative care?

Palliative care offers physical, emotional, psychological and practical support to people with any illness they're likely to die from.

By 2040 up to 10,000 more people will need palliative and end of life care each year. This growing demand comes as the cost of living with a terminal illness is increasing and the costs of delivering palliative care are also rising rapidly.

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.

This unmet need 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.

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

2. What do the questions mean?

There are five questions in the consultation which are a combination of multiple choice and open text answers. Views on all five questions are welcome and strongly encouraged, but important to note that you do not have to answer all the questions.

The next section of this guide will explore what the questions mean, and aspects you may wish to consider for your response. As part of this, you or your organisation may want to think about evidence which would strengthen your answers further. This could include:

- Stories of people with lived experience of dying, death and bereavement.
- Data and/or excerpts from reports or academic papers you or your organisation may have written on issues related to dying, death and bereavement.
- External data sets of relevance from national bodies such as National Records of Scotland, Public Health Scotland, Office for National Statistics which may inform your response.

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Question 1: Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a legal right to palliative care?

What this question is asking:

- What do you like and/or dislike about the consultation's proposed concept of a legal right to palliative care in Scotland?

- What do you think should be delivered as part of a legal right to palliative care that would support terminally ill people's physical and mental health, and financial outcomes? What could exercising a right to palliative care look like?

- Do you think that a legal right to palliative care is necessary for terminally ill people in Scotland to get the support they need? Do you think it is the right mechanism to deliver this support, or would a different policy or piece of legislation (whether new or existing) work better?

In your response you might want to think about:

What you or your organisation knows about current experiences of palliative support, and if the current support people receive meets their physical, emotional and financial needs.

This could include:

- How people should be identified for a right to palliative care.

- How people access palliative support, particularly related to where they live in urban or rural locations, faith, sexuality, ethnicity, gender and age.

- The type of palliative care people receive (whether specialist, generalist- including unpaid care- or a combination) and how workforces are equipped and empowered to deliver this support.

- The quality and frequency of support provided.

- Any similarities or differences in where palliative support is delivered (whether at home, care home, hospice, hospital) and the impact this has, if any, on a person's physical and mental health, and financial outcomes.

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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?

This question is one of the most important, as it will inform what definition of palliative care is used for the purpose of any standalone Act for a right to palliative care, or amendments to Scottish Government legislation. But it is also one of the most complicated questions, as there is not a universal definition of palliative care, and palliative care can mean something different to each person.

Palliative care includes, but is not exclusively, about end of life care. End of life care is part of palliative care, for people who have entered the process of dying. The end of life phase can vary between months, weeks, days or hours, and there is often uncertainty in identifying when someone may die, as illnesses are unpredictable and changes can happen suddenly and unexpectedly[1].

What this question is asking:

- How does the World Health Organisation definition, in a broad sense, chime with your understanding of palliative care?

- Do you think the World Health Organisation definition is the most appropriate definition for legislating a right to palliative care?

- Do you think end of life care should be part of the palliative care definition for the right to palliative care, or should they be thought about separately?

In your response you might want to think about:

What you or your organisation wants the right to palliative care to deliver, and how the definition of palliative care will inform and support its implementation.

This could include:

- For example, prompt assessment from any appropriate professional involved in a terminally ill person's care, either standalone or as part of a wider health and social care assessment, to determine what palliative support is required.

- If defining palliative care through statutory instrument for the purpose of this policy would bring additional clarity to legislation in order to support deliver and implementation.

- Whether the same or different definition of palliative care should be considered for health and social care legislation, human rights legislation, and/or other forthcoming legislation that is relevant to how people experience end of life e.g. housing.

[1] Scottish Partnership for Palliative Care: What is Palliative Care?
https://www.palliativecarescotland.org.uk/content/what_is_palliative_care/

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Question 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?

What this question is asking:

- What impact would a right to palliative care have on end of life experience for people living with protected characteristics such as age, faith, gender, ethnicity, locality, caring responsibility?

- What do you think it could improve in relation to end of life experience for people living with protected characteristics? How should this happen?

- What practical and/or policy considerations does a right to palliative care need to reflect to ensure it does not worsen end of life experience?

In your response you might want to think about:

What you or your organisation knows about end of life experience of people living with protected characteristics, and what precautions should be taken to ensure the right to palliative care does not have a negative impact.

This may include:

- Examples of best practice and/or challenges faced by protected characteristic groups in accessing and receiving palliative support, and what the right to palliative care should seek to embed from existing practices, policy and/or legislation.

- Whether legislation should include a purpose clause that includes dignity, universality, and participation principles to ensure shared and consistent understanding of a right to palliative care while also building a culture of human rights.

- If people with lived experience of protected characteristics should be involved in the development of legislation for a right to palliative care.

There are examples which demonstrate the variation in access to and receipt of palliative support **here**, and an overview of key issues **here**.

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?

What this question is asking:

- Do you think Integration Authorities (in current health and social care infrastructure) should continue to be responsible for the delivery of palliative care? Are there other bodies which should have an equal or greater responsibility?

- What opportunities and challenges might there be in legislating a right to palliative care for the bodies responsible for delivering, implementing and measuring the right?

- Is existing evidence related to palliative care robust enough to assess implementation of a right to palliative care? Are there gaps?

In your response you might want to think about:

- Whether bodies responsible for delivering palliative care should have a legal duty to comply with a right to palliative care, and whether this would reflect specialist palliative care, generalist palliative care or a combination. This may also include assessing the specific services appropriate to a person's palliative care needs without delay, and close to their home.

- How responsible bodies would demonstrate they are providing palliative care services, for example, quarterly/bi-annual/annual reporting and who would be accountable.

- Minium service, workforce and commissioning standards for the right to palliative care which could be modified to meet each local population's needs, and would include required human, time and financial resources to deliver services appropriately.

- The robustness of current data and evidence related to Future Care Planning, unscheduled care, health inequalities and inequities, carers, and public attitudes towards dying, death and bereavement. You or your organisation may want to refer to others specifically related to end of life experience, or your area of expertise.

Question 5: Are there any other comments on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?

What this question is asking:

- What financial resources would the right to palliative care require to meet local population health needs, and who should be responsible and accountable for this?
- Are there any environmental impacts the right to palliative care needs to consider?
- Are there additional factors which should be considered on how the right to palliative care would impact different groups in different ways?

In your response you might want to think about:

- Sustainable funding infrastructure for independent hospice care provision, including how any framework would reflect equitable access and delivery of hospice care and hospice care at home, how it would support financial security and viability of providers across Scotland to deliver a right to palliative care, and who would be responsible and accountable. Marie Curie's briefing on sustainable funding is **here**.
- What is working well and what needs to be improved in processes of commissioning palliative care, this may include a commitment from responsible bodies to ethical commissioning of services as part of the right to palliative care.
- How the right to palliative care should/would interact with other statutory rights in Scotland and the UK.
- Any other information you feel is relevant to end of life experience which you or your organisation has not mentioned in the previous questions.

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For any questions about this guide, or further information about the consultation process please contact:

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