Response to the Consultation on the Proposed Right to Palliative Care [ Scotland ] Bill
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RESPONDING AS AN INDIVIDUAL

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. χ 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.
YES I HAVE READ THE PRIVACY NOTICE REFERRED TO ABOVE

SEND TO

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my responses to CONSULTATION ON RIGHT TO PALLIATIVE CARE IN SCOTLAND 4 June 2024

Q 1
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?

A1
STRONGLY AGREE

I believe that every person should be treated with dignity and respect no matter what their situation and, therefore, I believe that each person on Scotland should have a right to palliative care.

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Q 2
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?

A2
I agree generally with the WHO definition of palliative care as the basis of statutory guidance in England on palliative care provision for Integrated Care Boards to implement their duty to commission palliative care services as legislated in the Health and Care Act 2022. The guidance to the Health and Care Act 2022 says :

" Palliative care 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."

However, there may also be need to be concerned with financial provision for those whose illness creates greater need for financial support such as higher energy bills and housing adaptations. in areas of deprivation and rural/remote areas.

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Q3
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)?

A3
**Strongly agree.**

Research by Marie Curie shows " that certain groups face particular barriers in access to palliative care, including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities, those who are homeless or in prison, BAME groups and LGBTQ+ people. ", those in rural/remote /high deprivation areas. I agree that extra support of various kinds may be needed in such situations.

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Q 4
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.

A4
I understand that " 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 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."[consultation document ]

However, there is much need for improvement-- at present Marie Curie says that about 1 in 4 people in Scotland do not received that palliative care they need
Do Integration Authorities have a significant or full understanding of population health need?
Is the required workforce already in position?
Is the required funding already in position?
Are inequalities in access and experience of palliative care being tackled appropriately?
Is the third sector included in strategic planning and commissioning of palliative care services?
There is need for collaborative working and innovation with all key stakeholders including independent hospice and hospice care at home providers as well as statutory providers

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Q5
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?

A5
Although the challenges are great there is much that can be done. For example Marie Curie has already established areas to focus on over the next five years.
Marie Curie is focusing on the following areas over the next five years with the aim of reducing pressures on the NHS for people at the end of life:

- **Rapid response nursing services** – reactive services to support dying people in their homes which helps to prevent unnecessary hospital admissions, including overnight and at weekends
- **24/7 single point of access hubs** – which can be accessed by carers and patients to reduce the complexity of navigating healthcare services and providers. Early evaluations of a service in Liverpool that the charity is involved in, which uses this method, has shown a 44% reduction in the average unplanned admissions in last 90 days of life

- **Working with the NHS and other providers** – to make services in the NHS and other organisations work better for people at the end of their lives, their loved ones, carers and also the taxpayer
- **Increase Advance Care Planning** – encouraging conversations between people and their families and / or carers about their future wishes and priorities for care. This will enable better planning and provision of care to help them live and die well in the place and manner of their choosing
- **More targeted support** – providing equity of access for all people, particularly those living in areas of deprivation or underserved groups
- REFERENCE: More than one person every minute will die with palliative care needs (mariecurie.org.uk)
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