Question 1

Do you agree that terminally ill adults, children, and young people with life shortening conditions residing in Scotland should have the right to palliative care?

Strongly agree.

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

Daily in Maggie's centres across Scotland and the UK we witness the positive impact of palliative and end of life care on quality of life for people with cancer and their families when: -

- *Offered as an early and integrated part of the supportive care continuum[1], with all sectors working together as equal partners (e.g. NHS, Third sector/Not for profit, Independent and Local Authorities).*
- *It uses a holistic, uniform and clinically governed approach[2] addressing physical, emotional, social, and spiritual dimensions accessible to the person with the diagnosis **and** their family[3].*
- *Care and bereavement support[4] is provided for the person's family after their death.*
- *It is fully aligned with research evidence [5,6]and consensus quality standards (QS13)[7] and guidelines[8], for example, NICE guidance on service delivery (NG142)[9], Supporting Adult Carers (NG150)[10] .*

However, we also know that despite its positive impact on people's lives,[5,6] at potentially the most traumatic time of their lives, coupled with the evidenced cost effectiveness[11] that make it an essential component of comprehensive healthcare delivery, not everyone in Scotland can access the palliative and end of life care they need and have a right to expect. So, we fully support the proposed 'Right to Palliative Care (Scotland) Bill'.

Maggie's has nearly 30 years' experience as a not-for- profit health professional provider of cancer support working alongside the NHS and other sectors. Based on this experience combined with our understanding of existing policy and evidence, we think a 'Right to Palliative care' should offer the person and their family equity of access to palliative and end of life care that is aligned with consensus, evidence-based guidelines, not restricted to any diagnostic group, readily accessed when needed to avoid unscheduled care[12], and delivered by staff with the required competencies supported by the NES learning and development[13] framework for palliative and end of life care, particularly the skills and confidence required to communicate in a sensitive and timely manner.

But most importantly people and their families need to know they have this right, and some may need help in identifying themselves as a person who warrants palliative care,[14] or in identifying themselves as a carer[15,16] and therefore entitled to support to

sustain the pivotal role they play. The promotion of Future Care Plan[17] as an integrated and routine part of care will assist with this awareness, whilst also ensuring that the wishes of the person with the life shortening condition and their family are at the heart of decisions about their care.

Sleeman and colleagues[18] recently reviewed fifteen UK palliative and end of life policies and their conclusions provide a helpful overview of the three inter-related themes that should be considered when delivering the right to palliative care: "(1) integrated care – conceptualised as reorganisation of services as a way to enable improvement; (2) personalised care – conceptualised as allowing people to shape and manage their own care; and (3) support for unpaid carers – conceptualised as enabling unpaid carers to live a more independent lifestyle and balance caring with their own needs".

Maggie's is uniquely placed to contribute to this overall picture of Palliative Care. We are physically present at all cancer hospitals in Scotland and can provide in-person support when most other support is only available online or by phone. People can self-refer to Maggie's – they can just come in. Maggie's offers specific support for people living with non-curable cancer, to help them and those who love them to live meaningfully. This part of our integrated programme aims to provide participants with information, skills and strategies to more effectively cope with the challenges of living with this stage of cancer. It includes support on emotional wellbeing, managing energy levels, nutrition, work and finances, relationships and navigating palliative care.

A cancer diagnosis affects the whole household. With so much focus on the person with the cancer diagnosis, the needs of those caring for them can often be overlooked, not least by the carers themselves. Maggie's provides group, family and individual support to carers to develop the self-reliance and coping strategies they need to continue with their caring role and while maintaining their own physical and mental health.

Question 2

What is your view on the World Health Organisation definition of palliative care, that is the statutory guidance in England on palliative care provision, being the basis for the legal right to palliative care?

The WHO definition is a suitable starting point particularly as it is used to underpin the statutory guidance in England on palliative care provision.

Refinements might include:

- *Broadening the definition to include the importance of public health palliative care[19] and the emphasis it places on wider societal context of dying, death, and bereavement to improve earlier engagement with services, eliminate health*

inequalities and raise awareness of the need to manage social morbidity of life-shortening conditions such as loneliness, job loss and stigma.
- *Using of 'evidence based multidisciplinary health care' instead of the term 'approach' to reflect the language used in consensus guidelines e.g. NICE.*
- *Reflecting within the definition the place of palliative and end of life care within the whole supportive care continuum[1].*

Question 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, se 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 living with terminal illness(es)?

Strongly agree that the right to palliative care will have different impacts on different individuals in our society.

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.

Implementing the Right to Palliative Care (Scotland) Bill will have to recognise the potential for the 'Inverse Care Law', whereby the people most in need of the care are least likely to receive it. People from these groups need to be a meaningful part of the consultation, design, implementation and evaluation process helping to identify the unique challenges they face so that health inequalities and inequities can avoided as far as possible.

Question 4

What is your view on how the 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.

1. *Equal Partners*

The implementation of the right to palliative care provides the opportunity to bring all sectors (e.g. NHS, Third sector/Not-for-profit, Independent sector and local authorities) together as equal partners with sustainable funding to provide an integrated approach building upon existing best practice.

Maggie's works alongside the NHS and other sectors to provide health professional expertise and resource for the support of people with cancer and their families throughout their cancer experience including in the palliative and end of life stages, and after the person has died. We recognise the key role we play and would welcome the opportunity to continue and expand our contribution as an equal partner in an integrated service, including the opportunity to provide insight data from our centres to help inform the implementation of the right to palliative care.

For example, between October 2023 and March 2024, Maggie's centres across Scotland received 474 visits from people who are bereaved to attend courses facilitated by a clinical or counselling psychologist. Also, we received 218 visits from people with advanced cancer to attend our Ongoing with Cancer course which is specifically designed to help people with the psychological, relational, and practical challenges they face when their cancer is in the palliative and end of life stage. Also 24% of visits to Maggie's centres in the last year were from people and their families with advanced cancer who would benefit from the Right to Palliative care the Bill proposes, an increase of 166% on the previous year.

2. *Learning from the experience and guiding frameworks*

The experience of introducing right to palliative care in England following the Health and Care Act 2022 provides invaluable learning opportunities to inform the process in Scotland and offset implementation problems. Recent healthcare innovation in Scotland that have used the six core principles of Realistic Medicine[20] may also provide a source of learning: (i) building a personalised approach to patient care; (ii) changing style to shared decision-making; (iii) reducing harm and waste; (iv) tackling unwarranted variation in practice and outcomes; (v) managing risk better; (vi) becoming improvers and innovators in healthcare.

In addition to NICE guidance on palliative and end of life service delivery, the recently published (MASCC and ASCO[21]) quality standards and practice recommendations for supportive care for people with advanced and metastatic cancer provides a potential framework generated through a consensus process that can be utilised when considering the implementation, governance, and sustainability of the right to palliative care in Scotland. The standards are across seven domains: person-centred care,

coordinated and integrated care, evidence-based and comprehensive care, evaluated and communicated care, accessible and equitable care, sustainable and resourced care, and research and data-driven care.

Question 5

Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?

After 28 years of delivering an evidenced programme of support, Maggie's is trusted by the NHS to deliver safe, well-governed support for its patients. Our work eases the pressure on NHS Scotland staff, by providing additional support part of a cohesive pathway alongside NHS care.

The need for Maggie's and how our work already strongly supports and complements the proposed Bill:

1. With the highest ever numbers of cancer referrals and record NHS caseload, Maggie's is a proactive partner to the NHS supporting NHS clinicians with timely person-centred care for their patients and contributes to their improved experience and outcomes.

2. A patient diagnosed with cancer and their family lives with a lot of uncertainty at every stage of their treatment.

3. Research shows that 3 in 5 (**58%***) people who have or have had cancer feel that the mental challenge of cancer is harder to cope with than the physical treatment and side effects.

4. Maggie's programme of is embedded in the NHS's cancer pathway to support patients with any emotional or psychological difficulty they may experience at any stage of their cancer. Maggie's supports patients through difficult times from their initial diagnosis right through to end-of-life.

5. From the point of diagnosis Maggie's plays a crucial role in helping people to 'wait well' for scans and treatment delays; giving them the support and information they need to decrease their anxiety and uncertainty and helping them to regain a sense of control.

6. At Maggie's all our support is free, and no appointment is needed. There is also no time limit on our support; we are here for as long a patient needs us. Many patients referred to Maggie's for one reason will access further support from the programme to meet their individual needs.

7. At Maggie's there's no waiting time for our support.

8. Maggie’s has a dedicated highly skilled workforce, including clinical psychologists in each centre.

9. Maggie’s support also includes the family and carers of people with living with cancer, ensuring that everyone is helped and no one is left behind.

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