A right delayed is a right denied: Marie Curie's consultation response to the proposal for a right to palliative care.

Friday 24th May 2024

Executive summary

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[1].

There is currently significant unmet palliative care need 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[2]. Unmet need leads to significantly poorer physical and mental health, and financial outcomes for terminally ill people, their families, and carers.

A right to palliative care should provide a clear legal underpinning for the principle that as a society, the care we provide to people who are dying is as important as the care we provide to those being born, and throughout their lives. That should not depend on age, where you live, your income, your housing situation, your diagnosis; a right to palliative care is part of the human right to health.

Marie Curie believes that everyone should have the best possible experience of end of life that reflects what is most important to them.

Minimum Service Standards will be the core implementation mechanism for a right to palliative care. Integration Authorities would have a duty to ethically commission palliative care to meet their local population health needs, recognising this could be different across

[1] 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

[2] 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

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each area. And the Scottish Government would have a clear responsibility for ensuring these obligations were fulfilled, and every person's right is respected and protected.

These should guarantee a minimum standard of access, receipt and delivery of palliative care, and apply to both specialist and generalist palliative care.

Our consultation response details the rationale for Minimum Service Standards; what they should include, resources required to implement it, and how it should be measured and monitored.

Key points which outline the rationale and resources required for Minimum Service Standards for palliative care:

1. Integration Authorities[3] should have a duty to ethically commission Minimum Service Standards of palliative care which meets their local population health needs, recognising that this will be different in each area.

2. Sustainable palliative care funding is vital to ensure the safe and efficient delivery of a right to palliative care, and the best patient health outcomes.

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

4. Marie Curie recommends the World Health Organisation (WHO) definition of palliative care be used to inform the scope of a palliative approach to a right to palliative care. Domains encompassed within the definition must be balanced depending on each individual's priorities and needs.

5. An intersectional lens must be applied to the right to palliative care, with trauma-informed care embedded in the Minimum Service Standards to ensure equity of support.

6. Minimum Service Standards for palliative care must be responsive to the nuances of 'place' of care and death for each individual, and ensure sufficient resource to deliver person-centred support which reflects patient choice.

7. Development of the right to palliative care should involve terminally ill people, their families, carers and all health and social care professionals who support terminally ill people, in accordance with the PANEL principles (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality).

8. Partnership working, mutual respect and recognition between organisations and individuals will be at the heart of delivering person-centred palliative care as part of a person's right, and Health Boards' and Integration Authorities' duty.

[3] or any successor bodies to Integration authorities created by the National Care Service legislation or any future legislation. This applies throughout this document where Integration Authorities are discussed.

9. There is a need for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery for the right to palliative care.

10. Training in palliative care should be a mandatory requirement for all workforces supporting a terminally ill person, including care home staff and social care staff, with provision for unpaid carers.

This is a crucial opportunity to work towards a Scotland where dying, death and bereavement are talked about openly, people can plan and discuss their care wishes, and palliative care is accessible whoever and wherever you are.

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?

This is Liz's story[4].



Photo credit: Margaret Mitchell

Liz, 73, was diagnosed with terminal lung cancer and struggled to get palliative support at home.

She was estranged from most of her family and lived alone as her partner lived separately. Her partner also has her own care needs. Liz spoke a lot about being alone, not knowing

[4] Liz's story is taken from **Dying in the Margins**, which examines barriers to and experiences of dying at home for terminally ill people, their families and carers living with acute financial hardship and deprivation.

what would happen when she reached the final stage of her illness, and her concern for what would happen to her partner after she died.

She wondered if her care and support was impacted by her living in a poorer neighbourhood, known for its high crime rates:

"What if I lived in Milngavie and was surrounded by loving sons and daughters that have done really well and had a beautiful house, was a professional person. I suspect my care would be different.
The Mitchell Library in Glasgow was a place she found warmth, away from her flat. It was there that she researched her condition and local neighbourhood.

In the last weeks of her life, Liz tried to remain at home. The care package she was offered from a home care provider initially involved half an hour's care, twice a day. But this was quickly dropped to half an hour, once a day, reportedly due to staff shortages. This package didn't meet Liz's needs, so when she was offered a hospice bed, she took it.

Although Liz was happy to be looked after in the hospice, any real choice about where she wanted to be at the end of her life had been taken away from her.

Key points in question one:

- **Marie Curie strongly agrees terminally ill people living in Scotland should have a right to palliative care.**
- **Marie Curie believes a right to palliative care must include Minimum Service Standard for palliative care which Integration Authorities have a duty to ethically commission.**
- **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.**

1. Marie Curie strongly agrees that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a legal right to palliative care as described in the policy intent of the proposed Bill.

2. Liz was unable to have the end-of-life experience she really wanted, to be able to die at home. Her experience is common across Scotland, and evidences the growing impact of social determinants on health outcomes.

3. Scotland should be a place where dying, death and bereavement are talked about openly, people can plan and discuss their care wishes, and palliative care is accessible whoever and wherever you are.

Palliative care need in Scotland

4. 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[5].

5. There is currently significant unmet palliative care need 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]. Unmet need leads to significantly poorer physical and mental health, and financial outcomes for terminally ill people, their families, and carers.

6. A right to palliative care is a crucial opportunity which must be taken to address unmet palliative care need across Scotland.

7. In 2022-23, there were almost 63,000 deaths registered in Scotland[7]; around 90% of those (56,700) had a palliative care need. Palliative care offers physical, emotional, psychological and practical support to people with any illness they're likely to die from. This includes Alzheimer's Disease, other dementias, heart, liver or kidney disease, motor neurone disease and advanced cancer.

8. 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.

9. End of life care is part of palliative care. It 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.

10. Palliative care can be provided in different settings, including in hospital, a hospice, care home 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:
    - 10.1. Managing physical symptoms such as pain
    - 10.2. Emotional, spiritual and psychological support
    - 10.3. Social care, including help with things like washing, dressing or eating
    - 10.4. Physical, emotional, spiritual and financial support for family and friends.

11. Existing evidence has demonstrated the benefits of the timely/early introduction of palliative care, including integration alongside active treatment when appropriate.

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[5] 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

[6] 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

[7] National Records of Scotland: Vital Events Reference Tables 2022-23

Studies have shown that early access to palliative care can result in higher quality of life, less aggressive end of life care, lower rates of depression, longer survival, and higher satisfaction with care among patients. The American Society of Clinical Oncology, for example, recommends palliative care involvement in a patient's care within eight weeks of a diagnosis of advanced cancer[8].

12. Scotland's ageing population means more people will be dying in the years to come. Marie Curie research projects over 60,000 people will die with palliative care needs by 2040, with over 85s accounting for 45% of all deaths[9].

13. People dying with multi-morbidities (more than one terminal condition) will have increased by over 80% in the next 20 years[10].

14. Marie Curie research projects that by 2040, nearly two-thirds of all deaths in Scotland will take place in care homes, people's own homes or hospices. This represents a significant, continuing increase in demand for community-based palliative services including social care, for terminally ill people, which will also become more complex over time[11].

"Me and my husband both have cancer he has bladder cancer I have blood cancer we both get treated but there's not enough back up financially for us or people going through same that cannot work.

"My mother died of breast cancer during lockdown and the palliative care was not there...me and my husband worry this is what will happen to us, and we're already on the breadline. - Marie, Ayrshire

15. Being terminally ill also substantially increases the risk of poverty, not just for the person living with the condition(s) but also for families and carers. The double burden of increased costs associated with terminal illness, including housing adaptations and energy bills, and income loss from partially or fully giving up work, plunges people below the poverty line.

16. Marie Curie research has shown working age people with dependent children are most at risk of poverty at the end of life, and women are more likely to experience poverty than men due to long-standing, structural inequality in the labour market, lower individual retirement income, and disproportionate unpaid care responsibilities. These inequalities are significantly magnified at the end of life[12].

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[8] 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)

[9] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

[10] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

[11] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

[12] Marie Curie Dying in Poverty: https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-scotland-4th-pp.pdf

A forgotten inequity: rural and island Scotland

17. A large proportion of the increase in palliative care and support required will be in Scotland's rural communities which have more elderly populations, and Marie Curie research has found the greatest increase in demand for palliative care in the coming years will be in over 85s[13]. But these rural communities are often a forgotten inequity, experiencing unique challenges in palliative care access and delivery:

    17.1. 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.

    17.2. 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.

    17.3. 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.

    17.4. 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.

"We had a very prompt response from Marie Curie, and action was taken as well as just calling. This prevented carer fatigue at a difficult time of the patient's illness.

"Marie Curie providing support made us feel like we had a team again to support our patient"- Dr Celine O'Neill, GP at Coll Medical Practice.

18. Workforce pressures are particularly acute in rural areas, and lack of access to palliative support mean that palliative and end of life care needs are currently shaped by services which are available, which are less likely to include all of the support people need.

19. A right to palliative care could change this through a Minimum Service Standard, but only with equitable resourcing i.e. recognising that different localities may require increased resources compared to others in order to achieve an agreed Standard.

[13] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

20. To achieve person-centred palliative care, the right to palliative care must commit to a whole-system, public health approach with service integration and partnership working at its heart across Scotland.

A human rights-based approach to palliative care

21. The right to palliative care must be built on strong foundations. It must reflect terminally ill people's care needs, preferences and wishes with flexibility and agility to evolve over time as these change.

22. Under Article 12.1 of the International Covenant on Economic, Social and Cultural Rights[14], everyone has a right to "the highest attainable standard of physical and mental health". The legislation identifies an obligation for States to "respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons…to preventive, curative and palliative health services" and in relation to older people, an obligation to ensure "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity"[15].

23. In 2014 the World Health Assembly (WHA) published a resolution which recognised that "palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received", and identified palliative and end of life care as an "ethical responsibility of health systems"[16]. Member States are required to report their progress against the resolution, including the integration of Palliative and End of Life Care across the continuum of care[17].

24. While the right to palliative care in Scotland would be an individual's right in principle, its implementation is entirely dependent on being successfully embedded into a whole system infrastructure, and commissioned, funded, and resourced as part of core health and social care services, integrated care coordination and delivery, to improve patient health outcomes and system resilience.

"The system is difficult to navigate - especially for people with little understanding of how the health and social care system works. It can work but takes huge determination."- Family member who shared their experience with Marie Curie.

Minimum Service Standards for Palliative Care

25. A right to palliative care must include Minimum Service Standards for palliative care which has a duty to be commissioned by Integration Authorities or their successor

[14] ttps://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights#:~:text=relation%20to%20need.-,Article%2012,of%20physical%20and%20mental%20health.
[15] Scottish Public Health Network: Palliative and end of life care in Scotland, the rationale for a public health approach. Briefing paper 3: legislative framework https://www.scotphn.net/wp-content/uploads/2016/02/2016_01_14-Briefing-Paper-3-Legislativeframework.pdf
[16] Scottish Public Health Network: Palliative and end of life care in Scotland, the rationale for a public health approach. Briefing paper 3: legislative framework https://www.scotphn.net/wp-content/uploads/2016/02/2016_01_14-Briefing-Paper-3-Legislativeframework.pdf
[17] Scottish Public Health Network: Palliative and end of life care in Scotland, the rationale for a public health approach. Briefing paper 3: legislative framework https://www.scotphn.net/wp-content/uploads/2016/02/2016_01_14-Briefing-Paper-3-Legislativeframework.pdf

bodies. The Minimum Service Standards should be aligned to the SIGN Scottish Palliative Care Guidelines or successor equivalent guidance to guarantee a minimum standard of and access to palliative care to ensure every person's right is respected, protected, and fulfilled.

26. Minimum Service Standards should apply to both generalist and specialist palliative care, including a prompt palliative care needs assessment upon diagnosis with support close to a person's preferred place of care and death (the concept of 'place' will be explored further in this consultation response).

27. Minimum Service Standards will create accountability and transparency about what a person and their family should expect and experience when they need palliative care, what health and social care bodies should provide, and what Government should have an obligation to make sure those bodies are resourced to deliver.

"Dad was sent home at the end of [this month] on an oxygen machine for 16 hours per day. This quickly rose to 24 hours a day. Mum was led to believe someone would check with her in this first period to make sure everything was ok.

"There was more information on how the machine worked than on the patient. After being released from hospital in [this month] following a chest infection mum was still the only carer, including all personal care for my 90+ year old father. It took four weeks to get a care package in place. The assessment was carried out by the care company and not social services. Mum was close to a break down at this point."- Family member who shared their experience with Marie Curie.

28. Minimum Service Standards must be grounded in strong care coordination, which has both direct and indirect benefits to patients and workforce associated with early palliative care interventions, home-based palliative care initiatives and multidisciplinary working[18].

29. Minimum Service Standards would require clear identification of roles and responsibilities of the accountable and responsible bodies to ensure the efficient coordination of services.

30. Recent research demonstrates, however, that there are long-standing challenges with sustainable palliative care funding and workforce recruitment and retention which limits opportunity to meet high demand of palliative care in community settings, with many practitioners performing tasks which surpass the responsibilities and regulations of their role, including care coordination[19].

31. Without clearly defined roles and responsibilities, standards of care and practice cannot be guaranteed[20], which would have significant implications for their implementation as part of a right to palliative care.

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[18] Coordination of palliative care in community settings; NHS Scotland, HIS, PHEN, What Works Scotland: https://www.healthscotland.scot/media/1733/coordination-of-palliative-care-in-community-settings.pdf

[19] Care Coordination in Palliative Care: who plays the key role? Reeves, E et al, 2020, PMC

[20] Care Coordination in Palliative Care: who plays the key role? Reeves, E et al, 2020, PMC

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 right to palliative care?



Photographs by Margaret Mitchell

"I was thinking the other day, maybe if they actually sat down and told me... about my liver and then my pancreas and all that, they've not really explained how my illness will go on, if you know what I mean? I would like somebody to sit down."- Donna, 56

This is Donna's story[21].

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 while she has some support from her Community Link Worker, she feels there are things she hasn't been told by medical professionals, mainly about what she can expect in the future.

Key points in question two:

- **A lack of knowledge about palliative care and a reluctance to engage with services are long-standing issues which significantly impact end of life experience.**
- **We recommend the World Health Organisation (WHO) definition of palliative care be used to inform the scope of a palliative approach to a right to palliative care**

[21] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

- **The WHO definition of palliative care encompasses domains which must be balanced depending on each individual's priorities and needs, to enable the best possible quality of life reflecting what is most important to them.**
- **This approach must translate through to Marie Curie's proposal of Minimum Service Standards of palliative care, and any other accompanying guidance.**

*NB. 'World Health Organisation' has been abbreviated to 'WHO' throughout this question.

1. Donna's experience is a common example of a terminally ill person requiring a multidisciplinary approach to their palliative support, while trying to accommodate place of care and death wishes but coupled with experience of deprivation and financial hardship.

2. The concept of 'palliative care' means different things to different people. Different wishes combine with very individual needs. And delivery on a practical level is dependent on what resources are available. This makes a single, universal definition of palliative care difficult, which contributes to public confusion and misunderstanding about palliative care and its implications.

3. Death literacy is commonly described as a set of knowledge and skills that make it possible to gain access to, understand and make informed choices about end of life and death care options[22]. Populations with high levels of death literacy will have context-specific knowledge about the 'death system' where they live and the ability to put that knowledge into practice – both for their own benefit and to support those within the wider community who are impacted by death and dying[23].

4. 'Death systems' are defined as the means by which dying and death are understood, regulated and managed in a society. They include and involve several components – including people (e.g. health and social care practitioners, funeral workers, religious leaders), places (e.g. hospitals, hospices, mortuaries, cemeteries), times (e.g. death anniversaries and remembrance days), symbols and rituals (e.g. last prayers) and more[24].

5. Death literacy and death systems partly inform an individual's perception of palliative care, and as such this partly informs and reflects their end of life experience.

6. A lack of knowledge about palliative care 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 and palliative care still carries an association with crisis intervention and/or imminent

[22] Creating a death literate society; Marie Curie, Cardiff University, PRIME Centre Wales, Queens University Belfast: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf
[23] Creating a death literate society; Marie Curie, Cardiff University, PRIME Centre Wales, Queens University Belfast: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf
[24] Creating a death literate society; Marie Curie, Cardiff University, PRIME Centre Wales, Queens University Belfast: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf

death. This means the benefits of early engagement are often not fully understood, taken advantage of or missed altogether.

7. End of Life Aid Skills for Everyone (EASE) is a course designed to enable people to be more comfortable and confident supporting family and community members with issues they face during dying, death and bereavement[25].

8. The course teaches the basics of end-of-life care and addresses some of the fears and uncertainties frequently held by members of the general public. It aims to help people to[26]:
    a. Become better equipped to provide informal support to friends, family and community members dealing with death, dying and bereavement.
    b. Find it easier to deal with these issues when they have to face them themselves.
    c. Know where to find further information and support in relation to these issues.

9. A right to palliative care is a key opportunity to embed examples of best practice, such as EASE, to support more open conversations about dying, death and bereavement.

10. The WHO definition must be articulated clearly to ensure informed understanding, regulation and management for patients, families and workforce to improve quality of life. The Scottish Government, Integration Authorities, the NHS and Local Authorities would benefit from onboarding and disseminating more widespread public knowledge about palliative care.

11. Implementation of a right to palliative care should, therefore, include a duty on responsible bodies to communicate that a right to palliative care exists, what it means and what it includes- with specific focus on explaining palliative care to people affected by dying, death and bereavement, and the general public to improve death literacy and public perceptions of palliative care.

12. Palliative care, as with all health and social care, should be person-centred with patient choice at the heart of shared decision making between them (their families if they choose) and clinical teams. However, if a terminally ill person's understanding, regulation and management of dying, death and bereavement[27] is ill informed, they are less likely to engage with palliative care in a way it would most benefit their quality of life.

13. This is likely to result in a crisis intervention as a result, placing increased pressure on already burdened health and social care systems, particularly unscheduled care services, which cost the NHS £190million per year for people in the last year of life,

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[25] EASE by Good Life, Good Death, Good Grief

[26] EASE by Good Life, Good Death, Good Grief

[27] Creating a death literate society; Marie Curie, Cardiff University, PRIME Centre Wales, Queens University Belfast: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf

and are used twice as much by people living in the most deprived areas of Scotland, compared to the least deprived[28].

14. Marie Curie supports the use of the WHO definition of palliative care to inform the scope of a palliative approach for a right to palliative care, as it considers the holistic needs of a terminally ill person - not just their health and social care service provision needs. It is vital that bereavement sits alongside palliative care as part of this holistic approach, as multiple people experience bereavement while someone is dying (anticipatory grief) and after their death including family, friends and health and social care staff.

15. In 2022-23, almost 315,000 people experienced bereavement in Scotland[29][30]. 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, but it has also 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.

16. Bereavement has its own inequities, with it often being much easier to access support if there has been a referral to a hospice for a person's care, but there is widespread recognition that services are not consistent between hospices.

17. Bereavement support takes various forms, and can be tailored to suit each individual. This ranges from more formal counselling and/or psychological support to more informal listening support within communities, and access to resources such as books, podcasts and videos.

18. However, there is a lack of statutory investment in bereavement support, meaning much of it is charitably funded and delivered by third sector partners, and volunteers. If a person has a negative experience of bereavement and/or experiences complicated grief through being unable to access the support they need, it can impact their perception of palliative care more broadly and reinforce a reluctance to engage with services in the future.

19. Therefore, using the WHO definition of palliative care will help maximise the positive impact a right to palliative care could have on health and social care systems, individuals, and society more broadly by taking a whole-system approach, and creating shared responsibilities which have an impact not only on health and social care provision but also on housing, social security and caring.

20. In the context of a right to palliative care, we believe the WHO definition should also be modernised to reflect a person's financial circumstances, given one in three working age people die in poverty at the end of life every year in Scotland, and

[28] 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
[29] UK Commission on Bereavement Scotland: https://bereavementcommission.org.uk/media/tzekjiyy/ukcbscotland_briefing.pdf
[30] National Records of Scotland Vital Events Reference Tables 2022

one in eight pensioners[31]. Financial hardship adds to the distress of people approaching the end of life, and reduces quality of life.

21. Therefore, in addition to the WHO definition of palliative care, a right to palliative care in Scotland should also include reference to Government and public authorities' duties under equalities legislation, including the Fairer Scotland Duty, to place a legal duty on named public bodies in Scotland responsible for implementing a right to palliative care to actively consider how they can reduce inequalities on health outcomes caused by financial socio-economic deprivation.[32]

22. There are 8,200 people who die in poverty at the end of life every year in Scotland, thus the intersection of this duty with a right to palliative care as defined by the WHO with the above conditions, would ensure the impact of a person's financial circumstances are considered when determining their support needs. It could also support earlier palliative care interventions, by responsible bodies showing cognisance and understanding of the impact of inequality and inequity on health outcomes.



Photo credit: Margaret Mitchell

This is Marie's story.[33]

Marie, 46, was living with a rare form of cancer, but despite her symptoms and the uncertainty she experienced, she always tried to make the best of things. As a single parent, she made ends meet, partly through support she received from the Welfare Rights team at the Council who helped maximise her entitlement to state support.

[31] Marie Curie Dying in Poverty https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-scotland-4th-pp.pdf
[32] Introduction - Fairer Scotland Duty: guidance for public bodies - gov.scot (www.gov.scot)
[33] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

Marie didn't like being dependent on state support, but she wasn't able to work:

"Sometimes it feels like begging for money as I have always been fiercely independent with money and never ask anyone for handouts, but my needs now mean I must swallow my pride and apply."

Taxis were the biggest expense for Marie; getting to and from hospital appointments could be up to £100 per week:

"I'm unable to walk and wait on a bus. I feel a combination of dizziness and weak legs, so going to a bus stop and waiting, then the bus journey itself amongst people during a pandemic is too much for me."

Other costs she had to meet included heating, electricity, and the cost of clothes because her weight fluctuated dramatically as a result of her illness[34].

23. Marie's experience evidences why it is vital that a person's financial circumstances are reflected in the definition for a right to palliative care, as one of the most influential factors in whether a terminally ill person can, or wishes, to engage with palliative support or not.

24. The WHO definition describes multidisciplinary teams involved in a person's palliative care as "palliative care involves a range of services delivered by professionals that all have equally important role to play- including physicians, nursing, support workers, paramedics, pharmacists, physiotherapists, and volunteers- in support of the patient and their family."[35] However, this definition excludes other multidisciplinary professionals such as psychologists, allied health practitioners, chaplains and social workers who can all have a pivotal role in a person's end of life experience.

25. Similarly, while social care can be considered part of a person's physical support, there is no mention of the social care workforce and unpaid carers in this aspect of the WHO definition, in the context of the hands-on care they provide to terminally ill people day to day on an equal footing with the professionals listed in point 21. Unpaid carers specifically, save the health and social care system approximately £10 billion each year[36].

26. 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 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.[37]

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[34] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)
[35] WHO: definition of palliative care: https://www.who.int/news-room/fact-sheets/detail/palliative-care
[36] Oxfam: Time to Care Report, 2020
[37] 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

27. Carers of terminally ill people are also often 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[38], 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 burnout is also the most likely factor in a person with a terminal illness being admitted to hospital, hospice or a care home.

"A large part of my role is the support I provide for family and friends of patients. Often, they have been caring for their loved ones for many months or years and have reached a point of exhaustion, both physically and emotionally.

"My being there enables them to take a deep breath and recharge their batteries knowing that someone else is taking care of everything. Even if it's just for a short time".
-Mark, Marie Curie Nurse, Rural Scotland

28. The WHO definition does not explicitly refer to the unpaid palliative care *provided by* carers, only that palliative care "improves the quality of life of caregivers as well[39]." While support from clinical professionals may improve the quality of life for carers in a physical, emotional, spiritual context, it does not reflect the crucial role carers have in a terminally person's end of life experience, and the costs associated with this.

29. Costs for unpaid care are usually categorised into three main areas, and have risen sharply since the pandemic, placing increased financial and emotional burdens on carers of terminally ill people. Costs include[40]:
    - Work related costs (e.g. changes in employment such as going part-time or giving up work entirely)
    - Carer time costs (related to time investment required by carers)
    - 'Out of pocket costs' (direct outgoings including transport, food, medicines)

30. The financial burden of caring is currently recognised through the Carers Support Payment, and Carer's Allowance Supplement in Scotland, which some carers are eligible for. But once a caring role comes to an end it can have a significant impact on the carer's wellbeing, financial position, relationships and virtually every aspect of their life.

31. Much of the support provided to them while they were a carer is withdrawn following the death of the person they were caring for, putting them at risk of poverty and complicated grief; Marie Curie and University of Sheffield research has shown that carers continue to be at risk of poverty particularly in the first year after a bereavement[41].

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

[39] WHO: definition of palliative care: https://www.who.int/news-room/fact-sheets/detail/palliative-care

[40] Gardiner, C et al Equity and the financial costs of informal care giving in palliative care: a critical debate BMC Palliative Care 2020

[41] Gardiner, C et al: 2024: Financial and employment impacts of family carer giving, interim report

32. We believe the physical, emotional, and financial needs of carers should be fully articulated as part of the scope and definition, which a right to palliative care would be grounded in and underpinned by in legislation.

33. The WHO definition also does not explicitly reflect housing and social security professionals who are significant actors in supporting a person's end of life experience. Support required from these services at the end of life should be clearly identified, and included in any legislative definition for a right to palliative care.

34. We recommend the WHO definition of palliative care be used to define the scope of a palliative approach to a right to palliative care with the above conditions in points 1-26. A person's right would be exercised by choosing which aspects of this palliative approach are the most important to them to best support their quality of life. This approach should be described in the proposal of Minimum Service Standards for palliative care, which form the core of Marie Curie's proposal for effective implementation of a right to palliative care.

35. It is essential the definition of palliative care is articulated clearly to enable realistic understanding, regulation and management of palliative care to patients, their families and carers, and workforce to improve their quality of life. A right raises expectation, therefore it is crucial that expectations are realistic, managed, and communicated to ensure terminally ill people have an end of life experience which is dignified, and reflects what is important to them.

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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 a terminal illness?



Photographs by Margaret Mitchell

This is Margaret's story[42].

Margaret thought her cancer was caused by pollution - growing up in an industrial city, living on a busy, polluted road, and working above a bus station for many years:

"We went to school in the peasouper. You were all holding onto each other, it was so thick. You couldn't see anything."

In her neighbourhood, Margaret knew lots of other people who had also got cancer – "and that's only people who I know".

Margaret's main worry as she neared the end of her life was ensuring her teenage daughter would be secure financially after her death:

"Even though her whole world was ending, she was still a strong person, and you can still see the fight in her."

[42] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

Margaret had been careful with money her whole life and had been self-sufficient from a young age, leaving home at 16 and being steadily employed.

She worked with the hospice social worker to check she had got all the benefits she was entitled to. She was upset when she found out she wouldn't be able to access her pension which she had worked so hard for:

"I've never claimed unemployment benefits, ever. Talking about national insurance stamps, I'm fully booked up. I'm going to lose my old-age pension which I never, ever received."

Key points in question three:

- **Equity-informed palliative care is often not realised for those with the greatest needs at the end of life due to insufficient resources for social care and primary care, primarily impacting people living with protected characteristics.**
- **Trauma-informed care must be part of the proposed Minimum Service Standards for palliative care to ensure equity of support.**
- **Minimum Service Standards for palliative care must be responsive to the nuances of 'place' of care and death for each protected characteristic, and ensure sufficient resource to deliver person-centred support which reflects patient choice.**

Inequalities, inequities and their impact

1. As in other health and social care settings and services, inequities and inequalities impact on whether or not someone might receive the palliative and end of life support they need.

2. Deprivation, geography, gender, religion, ethnicity, sexuality, learning disability, diagnosis and age are all biological and social determinants that can have an impact on whether someone gets the care and support they need at the end of life.

3. Many of these inequalities were exacerbated during the pandemic and led to considerably worse outcomes for patients, including poor quality of care and experience at the end of life. The right to palliative care must be 'future proofed' to withstand any future public health crises, to ensure people's end of life experiences are as unaffected as possible.

4. Marie Curie and Loughborough University research found that 8,200 people die in poverty every year in Scotland, equating to one in three working age people and one in eight pensioners[43]. It also showed a clear overlap between the most deprived geographical areas in Scotland and people experiencing poverty at the end of life.

5. People with protected characteristics are most likely to experience poverty throughout their lives, and the more protected characteristics a person has the

[43] Marie Curie: Dying in Poverty at the End of Life https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-scotland-4th-pp.pdf

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more risk they bear[44]. This increased risk persists to – and is magnified by – reaching the end of life. Terminal illness does not cause these inequalities, but exacerbates their impact – contributing to a significantly higher risk of falling into poverty, or deeper into poverty, at the end of life.

6. It is vital that palliative and end of life care and support can be accessed by people living with protected characteristics; this includes physical, emotional and financial support to help people at the end of life and those close to them, whatever the illness, to have an end of life experience which reflects what is most important to them.

7. Headline indicators of health inequalities in Scotland are identified as healthy life expectancy (HLE), premature mortality from all causes (aged under 75) and mental wellbeing of adults (aged over 16). Public Health Scotland also identifies morbidity (disease) as an indicator of health inequalities[45].

8. All of these indicators can affect terminally ill people's experiences of dying (morbidity), death (mortality) and bereavement (wellbeing). Data has shown that premature mortality for those under 75, all-cause mortality (aged 15-44), and healthy life expectancy at birth has been decreasing since 2015-2017 for males, and since 2014-2016 for females[46].

Older people

9. Older people, particularly those over 85, have the same palliative care needs as younger terminally ill people and should have the same access to palliative care. However, research has shown older people have more unmet pain, and are less able to access and receive palliative care if they don't have a clear terminal diagnosis, such as dementia or cancer, because frailty is associated with the normal process of dying[47].

10. For some adults over 85, there is evidence which highlights a lack of discussion about preferences at the end of life, including place of care and death. This includes a lack of Future Care Planning, despite older people often having greater information needs to understand their current and future care needs, compared to younger people who are terminally ill.

11. Some older people cannot access information due to poor eyesight and hearing and becoming overwhelmed about the amount of information being given. Many materials also still use medicalised language, making it difficult to understand their end of life care options.

[44] The Inequality of Poverty: Sara Davies and David Collings, University of Bristol: https://fairbydesign.com/wp-content/uploads/2021/02/The-Inequality-of-Poverty-Full-Report.pdf
[45] Public Health Scotland: Measuring health inequalities https://www.healthscotland.scot/health-inequalities/measuring-healthinequalities
[46] National Records of Scotland: Healthy Life Expectancy in Scotland, 2019-21
[47] Marie Curie: Enough for Everyone, Challenging inequities in palliative care https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/challenging-inequities-in-palliativecare.pdf

12. Scottish Government must note, however, that while digital technologies are a lifeline to many, there is still a high prevalence of digital exclusion in older people. It is significantly more complex and difficult for people who have limited or no access to digital devices and/or connectivity to establish and maintain engagement with palliative care services. Digital exclusion can also lead to high levels of isolation and loneliness.

13. It has also been shown that often older people are less likely to be referred for palliative care support over the age of 85 dying from terminal conditions, than those under 65. There is a common misconception that the older a patient is, the more likely that their needs are being met. But when community palliative care referrals are made, delivery of them can be difficult often as services are prioritised for younger people, or as a result of communication issues between different care settings. Frailty is a complex, multidimensional problem associated with decline towards dependence and death.

14. Frail older people often die without a defined single terminal illness, but would still benefit from palliative care. However, they often do not have the same access to palliative and end of life support as younger terminally ill people.

15. Scotland has an ageing population, and particularly high elderly populations in rural and remote areas of Scotland. Marie Curie research has found that by 2040, the biggest increase in palliative care demand will be in over 85s[48], meaning a large proportion of future palliative care need is likely to be in rural and island areas.

16. However, while rural elderly populations are increasing, there is lower demand and accessibility to specialist healthcare, including palliative and end of life care, and terminally ill patients living in rural and remote areas are at significant risk of being hidden and forgotten[49].

Socio-economic deprivation

17. People experiencing deprivation and/or multiple disadvantage are less likely to engage with palliative care, or wider health and social care services, because of trauma and a lack of trust.

18. 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 health, and life[50]. 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.

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[48] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019) 28 https://spcare.bmj.com/content/3/1/129

[49] Remote and Rural: the Forgotten Inequity; J, Layden, H Bunch, D Hekerem, L Millar, V Maxwell: https://spcare.bmj.com/content/3/1/129

[50] https://www.health.org.uk/publications/tackling-the-inverse-care-law-in-scottish-general-practice#:~:text=The%20'inverse%20care%20law'%20describes,law%20in%20Scottish%20general%20practice.

19. The majority of people in 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.

20. 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 and island communities.

21. 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, and is unaffordable for many, meaning they die in poverty[51].

22. We believe 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.

23. Eliminating inequality and inequity in care planning and delivery 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.

Trauma-informed palliative care



Photo credit: Margaret Mitchell

[51] Marie Curie: The Cost of Dying 2019

This is Max's story[52].

Max,65, wanted to remain in his local community at the end of his life, to be with his friends and his dog Lily. He was an army veteran with prior experience of homelessness and trauma, and he felt trapped by institutions:

"I prefer being at home. No one wants to be in a hospital. I want to do my own thing."

But being at home was not always easy. There were four flights of stairs to manage, plus his front steps. This meant he was essentially housebound and not able to get outside:

"You see about the stairs, right, the stairs are a big, big problem."

The bath was also a problem as he couldn't get in and out of it to take a shower. His local housing association didn't appear to prioritise the adaptations he needed, or the maintenance issues he experienced in his final few months. Max wasn't well enough to keep things clean or tidy and it's possible that carers visiting him at home would have judged his environment 'unsuitable'.

Each time Max's cancer symptoms became too severe, or his carers could no longer manage, he was admitted to the hospice. He told Margaret that the title of his life story would be: "From hell to heaven and back to hell again."

Being in the hospice wasn't easy for Max either. He missed Lily terribly. At one point, Max made a 'great escape' from the hospice. As his friend said afterwards:

"He did a runner from the hospice basically to get back to his dog." Max found the hospice environment and policies too restrictive and walked off on his own, despite being in considerable pain and having difficulties walking.

From then on, his care team took a trauma-informed approach to his care, which was more flexible to his needs. Max was supported at home until the final week of his life, when he asked to be moved into the hospice because his symptoms were worsening. This provided some relief for his friends who had been caring for him.

24. There is an opportunity for trauma informed care be a foundational aspect of the Minium Service Standards of palliative care which Maries Curie propose - but this will require resources for awareness raising and workforce training for successful implementation. This approach would ensure equitability of the right to palliative care, in recognising that achieving an end of life which reflects what most important to each individual looks different for each person, and some will require more resources than others to make this a reality.

25. Many people affected by dying, death and bereavement experiencing financial hardship and deprivation would benefit from a trauma-informed approach to their

[52] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

care, yet few receive it. Trauma-informed palliative care recognises the impact of trauma in individuals with life-limiting illnesses, also extending to their primary caregivers and multi-disciplinary professionals supporting them. Central to implementing a trauma informed approach are principles which aim to build trust, promote resilience and prevent re-traumatisation[5354]:

a. **Safety**; creating secure and comforting care environment.
b. **Trustworthiness and transparency;** fostering trust and clear communication.
c. **Peer support**; leveraging support networks for healing.
d. **Collaboration and mutuality**; encouraging shared decision-making.
e. **Empowerment**; focusing on patient strengths and coping skills.
f. **Attention to historical, cultural, and gender contexts**; acknowledging the diverse experiences of patients[55].

26. There are significant challenges accessing independent advocacy, with terminally ill people, their families and carers experiencing deprivation and financial hardship therefore facing difficulties navigating complex, interacting health and social care, social security and housing systems and not getting the support they need both during and after death. System complexity is intensified further for people living with multi-morbidities, who require support from multiple services often resulting in them falling through the cracks[5657].

27. Implementing a trauma informed approach requires whole-system integration across health and social care, social security and housing in particular, and education for professionals which empowers them to recognise and appropriately respond to trauma presentations[5859].

28. This should encompass developing training, trauma assessment techniques, and intervention strategies specific to palliative care to improve end of life experience for patients and caregivers ensuring a trauma-informed environment that supports psychological safety and minimises the risk of re-traumatisation[6061].

29. Independent advocacy and system integration will be pivotal to implementing equitable Minimum Service Standards as Marie Curie is proposing as part of a right to palliative care, and must be resourced appropriately.

[53] "The great escape": how an incident of elopement gave rise to trauma informed palliative care for a patient experiencing multiple disadvantage. Quinn, S et al: BMC Palliative Care 2024
[54] Trauma informed palliative care is needed: A call for implementation and research; De Groot, J et al, Palliative Medicine 2023
[55] Substance Abuse and Mental Health Services Administration, 2023
[56] Trauma informed palliative care is needed: A call for implementation and research; De Groot, J et al, Palliative Medicine 2023
[57] "The great escape": how an incident of elopement gave rise to trauma informed palliative care for a patient experiencing multiple disadvantage. Quinn, S et al: BMC Palliative Care 2024
[58] "The great escape": how an incident of elopement gave rise to trauma informed palliative care for a patient experiencing multiple disadvantage. Quinn, S et al: BMC Palliative Care 2024
[59] Trauma informed palliative care is needed: A call for implementation and research; De Groot, J et al, Palliative Medicine 2023
[60] Trauma informed palliative care is needed: A call for implementation and research; De Groot, J et al, Palliative Medicine 2023
[61] "The great escape": how an incident of elopement gave rise to trauma informed palliative care for a patient experiencing multiple disadvantage. Quinn, S et al: BMC Palliative Care 2024

Understanding need

30. To deliver equity informed palliative support, implementation of a right to palliative care must consider the impact of people's and communities' needs which are more heavily influenced and impacted by social determinants of health, as well as resources required to meet a Minimum Service Standard of palliative care which will be different across each protected characteristic.

31. To better understand local population palliative care needs, there must be improved data capture which takes a whole-system approach to build an accurate picture of living with terminal illness across communities.

32. Connected Bradford is a whole system data linkage accelerator which links data to understand local health needs, identify and predict those most in need of support, and evaluate health interventions.[62]

33. There has been extensive investment to unlock the potential of clinical data for health research in the UK, however, most of the determinants of our health are social, economic, education, environmental, housing, food systems and are influenced by local authorities[63].

34. The Connected Bradford Whole System Data Linkage Accelerator was set up to link health, education, social care, environmental and other local government data to drive learning health systems, prevention and population health management[64].

35. This prospective data collection captures near real time activity[65], and would support identification of local palliative care needs to inform how a Minimum Service Standard of palliative care should be implemented, and resources required, as part of a right to palliative care.

Place of care and death

36. Place of care and death is a complex concept which has different connotations and implications for each person. It is one of the most common indicators used to measure quality of end-of-life experience, including whether a person's care wishes were met relating to where they wanted to receive palliative support, and to die. However, there are several variables which determine whether a person can or should die at home, which are important to consider.

37. Urban health and social care infrastructure and funding models are often transferred ineffectively to rural and island areas, deepening existing inequity for these communities. As a result, rural and island communities often have choice about care and support at the end of life removed, with many determined by resources which are available not necessarily what an individual needs for quality of

[62] Connected Bradford: A whole system data linkage accelerator; Sohal, K et al; Wellcome Open Research
[63] Connected Bradford: A whole system data linkage accelerator; Sohal, K et al; Wellcome Open Research
[64] Connected Bradford: A whole system data linkage accelerator; Sohal, K et al; Wellcome Open Research
[65] Connected Bradford: A whole system data linkage accelerator; Sohal, K et al; Wellcome Open Research

life. For example, if a person lives more than 10-15 minutes from inpatient palliative care in rural and island communities, they will almost certainly die at home regardless of whether that is their wish[66].

38. In NHS Highland, for example, the place a person dies is highly impacted by the area in which they live, especially the degree of remoteness. The cause of death impacts the place where people die. People dying with dementia are more likely to die in a care home and much less likely to die in hospital; those dying of cancer are less likely to die in hospital and more likely to die at home; and those dying of organ failure are more likely to die in hospital and less likely to die at home[67].

39. The concept of 'home' must also be considered in the context of locality- at a Marie Curie stakeholder roundtable on the end of life experiences of rural and island communities, one participant shared their experience of a parent's end of life, where 'home' meant place of origin and returning to one of the Scottish isles. This was their wish, with no specific preference for which care setting support was delivered in.

40. 'Home' may also, for some, not be a safe place. This is particularly prevalent in deprived urban areas which experience higher crime rates[68]. Andy, a participant of the Dying in the Margins, had no choice but to spend his final weeks at Marie Curie Hospice Glasgow, as his flat had been broken into and it was not fit for purpose. He had nowhere else to go[69]:

[66] Chukwusa, Emeka; Verne, Julia ; Polato, Giovanna ; Taylor, Ros ; J Higginson, Irene ; Gao, Wei *Urban and rural differences in geographical accessibility to inpatient palliative and end of life care facilities and place of death: a national population-based study in England*
[67] End of Life Care Together: Accounting for Value https://www.nhshighland.scot.nhs.uk/media/pg4ndbzy/supporting-end-of-life-care-in-nhs-highland-accounting-for-value-report.pdf
[68] Why do inequality and deprivation produce high crime rates and low trust? Benoit de Courson and Daniel Nettle, 2021, Scientific Reports: https://www.nature.com/articles/s41598-020-80897-8
[69] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

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Project Diary: Margaret Mitchell



Project Diary: Margaret Mitchell

41. Andy's preference was to die in his flat, which he considered home, but as clinicians have a duty of care to patients, a joint decision was made he would receive palliative support at the hospice.

42. When 'place' of care and death is addressed in research or public policy, it is most commonly thought of in the context of 'care setting' including home, care home,

hospital, hospice, and prisons. Marie Curie research has shown that deaths in community settings specifically will continue to increase, accounting for two thirds of all deaths by 2040[70].

43. Minimum Service Standards for palliative care must reflect the nuances of 'place' of care and death, and ensure sufficient resource to deliver person-centred support which reflects patient choice, where possible and appropriate.

Palliative care for people in prison

44. Prison populations are ageing and have much poorer health when compared to the general population, often living with multiple, complex co-morbidities, creating a greater demand for palliative care in this setting.[71]

45. A more integrated approach between all care providers, prison staff and custody must be facilitated and implemented to ensure terminally ill inmates requiring support can easily access care in an appropriate environment. In Scotland, evidence shows prison populations are following similar patterns to England and Wales, with significant increases in those over 50[72].

46. Currently, there are significant challenges in delivering palliative and end of life care in prisons which is a result of a combination of factors.

47. The majority of prison building structures are either expensive to adapt for patients with mobility issues or cannot be adapted at all because of existing design constraints[73]. There are difficulties with staff resources (including absence of overnight care) and accessing equipment.

48. Security constraints impact contact with family, peer support and health and social care professionals coordinating access to medicines[74]. The conflicting priorities between care and custody can have a negative impact on palliative and end of life care delivery in prisons, and have an impact not just on the person but also the wider prison population, including staff. There are also no hospital wings in prisons, which is a common misconception.

49. Strong relationships with people both inside and outside of prison has been evidenced as one of the most important factors to prisoners with palliative and end of life care needs, yet many do not have access to this support.

50. For a right to palliative care to effectively support palliative and end of life care needs in a prison setting, long-standing existing barriers need to be overcome:

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[70] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)
[71] McParland, C & Johnston, B Palliative and end of life care in Prisons; a mixed methods rapid review of the literature from 2014-2018 BMJ 2019
[72] McParland, C & Johnston, B Palliative and end of life care in Prisons; a mixed methods rapid review of the literature from 2014-2018 BMJ 2019
[73] Turner, M & Peacock, M Palliative care in UK prisons; practical and emotional challenges for staff and fellow prisoners Journal of Correctional Health Care, Vol. 23, No.1
[74] McParland, C & Johnston, B Palliative and end of life care in Prisons; a mixed methods rapid review of the literature from 2014-2018 BMJ 2019

facilities must be adequate (accessible cells with appropriate access to equipment); medicines need to be readily accessible 24/7; if required, onsite healthcare review is available (currently only if a patient becomes unwell or needs medical or nursing attention), the only option in Edinburgh is for that patient to go to hospital); loved ones supported to visit at bedside, especially in last days.

51. The right to palliative care must support and facilitate collaboration between prisons, hospice and palliative care providers, especially those with frail, elderly populations, to ensure the palliative care needs of prisoners are met. This may include being able to support rapid compassionate release, where risk assessment allows, that is appropriately resourced and should include social care.

LGBTQ+ people

52. In the context of experiences of LGBTQ+ people, Marie Curie research from the University of Nottingham and King's College London found that LGBTQ+ people can often feel apprehensive using health and social care services, including end of life care, because of previous experiences of discrimination[75].

53. When they do decide to access services, they can face many barriers to feeling like they can reveal their true identity. Often health and social care professionals will aim to treat everyone the same, however, this often misses some of the particular needs and wishes LGBTQ+ patients have at the end of life.

54. Approaches that promote heterosexuality as the normal sexual orientation can make it more difficult for people who are LGBTQ+ to disclose their true identity. LGBTQ+ people are also more likely to feel worried that their partner will not be acknowledged as important, and will not be properly supported after their death, due to assumptions that the patient is heterosexual and not in a relationship with their partner.

55. LGBTQ+ people often miss out on having those closest to them around them when they are dying and involved in the process after their death. Future Care Planning for LGBTQ+ people is important as a way to provide protection for loved ones who might not be recognised otherwise.

56. Seeking spiritual and religious support is important for LGBTQ+ people however it is not always easy to access, and having their wishes respected after death was a particular concern for people who are LGBTQ+.

57. People who care for LGBTQ+ people with a terminal illness can also often be under more pressure because of a reluctance to access services.

[75] Marie Curie: Inequities in palliative care: LGBTQ+ https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefingsconsultations/scotland-briefings/marie-curie-briefing-inequities-lgbt.pdf

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People living with learning disabilities

58. People with learning disabilities often have additional needs in palliative and end of life care. Understanding and considering these needs when providing care, can improve people's quality of life. It can also make sure they're getting the person-centred care they need.

59. Learning disabilities can be mild, moderate, severe or profound. Someone with a mild learning disability might be able to do most everyday activities. But they may need support with tasks like managing finances or filling out forms. Someone with a severe or profound learning disability, will need more support with things like moving around, personal care and communication.

60. A profound and multiple learning disability (PMLD) is when someone has a severe learning disability and other disabilities. Someone with a PMLD might have difficulties seeing, hearing, speaking, moving, and communicating.

61. People with learning disabilities may have more complex physical and mental health needs, be more likely to be vulnerable and socially isolated, have difficulty accessing health and social care, and be diagnosed with a terminal condition at a later stage giving them a poorer prognosis.

62. People with learning disabilities also find it difficult to understand information about their health and treatment, find it hard to communicate how their symptoms are affecting them and struggle to express their end of life care wishes, making Future Care Planning more difficult.

63. Person-centred approaches to communication for people with learning disabilities must be embedded in Minium Service Standards for palliative care. Examples of best practice include planning ahead cards to help facilitate conversations between people living with learning disabilities and their families to think about the future, prepare for parental death, and transitions in care.[76]

Ethnically diverse groups

64. Ethnically diverse groups experience discrimination at the end of life and Marie Curie evidence has shown palliative care delivery is not always sensitive to their cultural and religious needs.

65. Language barriers also significantly impacted dialogue between patient and family and health and social care professionals, especially when trying to organise an interpreter at short notice, creating issues for those trying to access services at the end of life. Language barriers can make it difficult to have conversations around dying, death, and bereavement but also when it comes to Future Care Planning, and there are limited resources available to support practitioners to have open conversations with ethnically diverse groups.

[76] Growing Older: Planning Ahead Cards Professor Irene Tuffrey-Wijne

66. As part of the proposed Minimum Service Standards for palliative care, all health and social care staff responsible for a terminally ill person's care must be empowered and equipped to deliver culturally and religiously sensitive support at the end of life in order to meet the needs of ethnically diverse communities.

The impact of gender at the end of life

67. International evidence suggests that gender inequalities are present at the end of life, from presentation and acknowledgment of symptoms to preferences for and willingness to accept care. However, there have been no previous attempts to investigate gender differences in palliative and end of life care in Scottish and Welsh contexts.

68. Marie Curie research is the first step in investigating this issue further in Scotland, with aims of exploring gender differences in use of palliative care services, time from referral to death, preference for place of death, and place of death, and better understanding palliative care staff's views on the impact of gender on palliative care access and experiences.

69. The results found differing views on palliative care referral and access between genders, with some indicating men tended to receive support from palliative care services when their illnesses were at a more advanced stage than women. This was felt to be, in part, due to the higher level of support that men were thought to receive from women in the community which enabled them to stay at home for longer:

"The male patients who are admitted tend to be further down the palliative route because generally speaking… their wives or partners are better at looking after them … and manage for longer" – Allied health professional

70. By contrast, others felt men tended to be referred earlier than women, as women would be more proactive in seeking help and more accepting of receiving help from services than male carers:

"I do feel that a male partner or a husband is referred to our services earlier on in their journey compared to a female. And that a wife is a lot more accepting of allowing that care into the home" – Clinical Nurse Manager, Scotland

71. There was broad consensus that societal pressures led more women – particularly adult daughters – to take on the primary carer role, particularly for personal care interventions such as washing and bathing:

"Whilst the husband or partner may be their main carer […] in the background you will often find that there's a female relative running around doing the jobs, looking after the children, and still doing things in between."-District Nurse

72. The research also showed that some male carers were less likely to seek or accept support for themselves, friends and family more than women.

73. There is agreement that gender and its influence on accessing and experiencing care should be considered, but further recognition that other factors are likely to intersect and perhaps exert greater influence on experience of accessing palliative care are required.

74. The research showed for some, there was an intersection between age and gender, with younger people, particularly male carers with young families, being more likely to request and access support than older men:

"I find men who have got a younger family as well are more likely to seek help if they have young children and it's their partner that's end of life, then I find that they're more open to seeking help and seeking help for the children as well"– Clinical Nurse Manager, Scotland

75. Other factors, relating to ethnicity, class, geography, financial security, culture, personality and sexuality were considered more influential than gender may be. All participants recognised the holistic nature of palliative care and the desire to provide care that aligned with the needs of an individual and those close to them.

76. The research highlighted a lack of diversity among the patients and families staff supported, with the vast majority being white, heterosexual and cis gendered. This limited experience of supporting people outside of the white, heterosexual, cis-gendered majority meant that for some staff, confidence regarding how best to support a range of different people was limited.

77. Relating to gender, the evidence also showed that staff were worried about inadvertently offending someone through use of language or limited understanding of the individual and what was important to them. This was especially true regarding supporting transgender people, and anxieties around the use of pronouns.

78. A right to palliative care must take an intersectional lens which accounts for gender differences in palliative and end of life care to ensure everyone has an experience which reflects what is most important to them.

Non-malignant conditions

79. Terminally ill people living with non-malignant conditions such as COPD, Motor Neurone Disease, and dementias experience inequity of access to palliative support, largely due to misconceptions of palliative care only being for people living with terminal cancer.

80. This inequity also extends to place of care for terminally ill people living with non-malignant conditions, given many live in care homes with dementias for example, where the infrastructure does not support palliative care delivery. Needs Rounds combine direct clinical care, monthly meetings between clinicians and care home staff, and multidisciplinary and family meetings to deliver truly person-centred

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support based on each care home resident's palliative care needs[77]. This approach should be an embedded element of the Minium Service Standards for palliative care, and requires both generalist and specialist palliative care.

81. Marie Curie research has shown that only 47% of people living with organ failure had a Key Information Summary at the time of their death, compared to 80% of people living with terminal cancer[78].

82. Non-malignant conditions which can have longer trajectories such as COPD and dementia also have a more significant impact on carers, often worsening their physical, mental, and financial wellbeing due to people living longer with more complex care needs. This leads to carer burnout and often, crisis intervention:

"It is still very difficult to arrange community care for people who live alone at home who require support every night towards the end of life. This is especially true if the disease has a long trajectory like MND, MS, dementia or Pulmonary Fibrosis. The current system does not support carers sufficiently in situations like these."- Family member who shared their experience with Marie Curie.

83. There is insufficient evidence and research into access and delivery of palliative care for people living with non-malignant conditions, which should be addressed through the right to palliative care with ringfenced budget from Scottish Government to better understand these issues and move towards truly equity informed palliative support.

84. Marie Curie has long called for a human-rights based approach to palliative care with human rights and lived experience embedded in its core.

Principles of a right to palliative care

85. Development of the right to palliative care should involve terminally ill people, their families, carers and all health and social care professionals who support terminally ill people, in accordance with the PANEL principles (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality).

86. DEAB (diversity, equity, acceptance and belonging) principles should also be embedded as part of the approach to a right to palliative care, and will be a fundamental aspect of achieving equity informed palliative support:
    - **Diversity**: welcomes all the ways people are different (both visible and invisible) and promotes a wide range of different people and perspectives
    - **Equity**: recognises that each person has different circumstances and allocates the required resources and opportunities needed to reach an equal outcome.
    - **Acceptance**: understanding and valuing that each person is different, and ensuring people feel involved, respected, and connected to having their voice heard.

[77] Needs Rounds University of Stirling
[78] https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC6917358/

- **Belonging**: creates a culture where people can be themselves without judgment, have psychological safety and appreciate each other
- **Equity is of particular importance**, as it is often used interchangeably with equality, despite have completely different meanings, requirements and impacts (equality means each individual (or group of people) is given the same resources and opportunities- which in the context of palliative care, often does not deliver an end of life experience which reflects each individuals needs and wishes).

87. We believe points 79 and 80 should be reflected in a purpose clause of any legislation to ensure shared and consistent understanding of a right to palliative care while also building a culture of human rights.

88. The Right to Palliative Care Bill should be an empowerment to choice, not indicative of the support terminally ill will get. The right will not automatically reform services but will create a foundation on which to build sector reform to achieve a Minimum Service Standard of palliative care, realising long terms benefits for terminally ill people, their families and carers, and for our health and social care systems.

Question 4: What is your view on how a right to palliative care should be implemented?

This is Linda's story told by her daughter Nicola[79]:



"My mum Linda McLeod was born in Edinburgh and lived in Dundee. My Mum was 63 when in June 2019, she was diagnosed with secondary breast cancer and aggressive cancer in her spine.

[79] Dying in the Margins: Marie Curie and University of Glasgow.

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"As soon as she told me, I rushed home from London in the car at 2am with my three young children.

"My mum knew she had terminal cancer and that she was going to die, but she also knew that she didn't have any money to pay for anything - including her funeral. Because my mum didn't have a financial safety net, there was no income when she was diagnosed. It was really difficult for us to manage as a family.

"I would drive to Scotland with the children and stay for five days while my husband was at work. If we'd had more money, we could have arranged childcare. The cost of the travel, flights and looking after my mum in the hospital was huge.

"My mum lived on the fourteenth floor of a tower block. The lift only went to the thirteenth floor. Moving back home with all the equipment she would have needed would have been practically impossible. The space would have been too small for me, my mum and three children and we couldn't afford childcare to allow me to focus on caring for her.

"In the end, she was transferred to a hospice ten days before she died. The hospice was brilliant, and I'm so glad she didn't die in hospital, but I know she would have wanted to be at home.

"I just couldn't do that for her with what we were offered".

Key points in question four:

- **Integration Authorities[80] should have a duty to ethically commission Minimum Service Standards of palliative care which meets their local population health needs, recognising that this will be different in each area.**
- **Partnership working, mutual respect and recognition between organisations and individuals will be at the heart of delivering person-centred palliative care as part of a person's right, and Health Boards' and Integration Authorities' duty.**
- **Training in palliative care should be a mandatory requirement for all workforces supporting a terminally ill person, including care home staff and social care staff, with provision for unpaid carers.**
- **There is a need for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery for the right to palliative care.**

1. Linda's experience of being unable to receive the palliative support she needed lays bare the long-standing challenges with unmet palliative care need, particularly related to health and social care integration, care coordination and delivery.

Role of Integration Authorities

2. Across Scotland, there is wide variation in standards across different Health Boards, Integration Authorities and providers. Agreeing a Minimum Service Standard for palliative care including education, quality of care and governance will bring improvement and reduce unwarranted variation. This will happen most effectively

[80] or any successor bodies to Integration authorities created by the National Care Service legislation or any future legislation. This applies throughout this document where Integration Authorities are discussed.

when there is an overarching nationally agreed approach which is implemented locally.

3. Since health and social care in Scotland became integrated in 2016 by the Public Bodies (Joint Working) (Scotland) Act 2014, 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[81].

4. Palliative care is not explicitly stated as a legal requirement of Strategic Plans, but is referred to in the Public Bodies Act as one of the sets of services which must be delegated to an Integration Authority. The Scottish Government issued a palliative care commissioning advice note in 2018[82]. 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.

5. Marie Curie believes Integration Authorities should retain responsibility for delivery of palliative care, to be used as a vital opportunity to improve health and social care integration which is essential to delivering palliative care. There should be a duty on Integration Authorities to ethically commission to at least a Minimum Service Standard of palliative care.

6. This approach should provide a single, collaborative model to address existing and significant gaps in palliative care and commissioning through integrated leadership.

7. However, these must include representatives from all sectors, including the third sector, to enable a whole-system approach to effective delivery of the right to palliative care.

8. We believe the third sector must be included as equal, voting members of all Integration Authorities in Scotland to deliver, implement and monitor a right to palliative care, alongside NHS and Local Authority representatives and people with lived experience.

9. This will support a more strategic, whole-system approach to developing and delivering Minimum Service Standards of palliative care which are focused on outcomes and needs of people in communities.

10. The third sector plays a key role in innovation and delivering 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 services. This has often been Marie Curie's experience of supporting the development of palliative care services in different health and social care partnership areas.

[81] Public Bodies (Joint Working) (Scotland) Act 2014
[82] https://www.gov.scot/publications/strategic-commissioning-palliative-end-life-care-integration-authorities/

11. Marie Curie is the largest third sector provider of palliative care services for adults in Scotland, as well as being the leading charitable funder of palliative and end of life care research. Much of the third sector engagement with existing IJBs at Board level is channelled through the Third Sector Interfaces (TSIs), which act as the official representatives of the sector on those Boards. However, TSIs are not always effective in being able to directly represent the whole sector.

12. Marie Curie's engagement with TSIs has been minimal. In our experience, many, although not all, TSIs believe that national charities such Marie Curie are either not present locally or have direct communication with IJBs therefore do not actively engage us in consultation work or activity with existing IJBs.

13. We believe that new ways of engaging with the third sector should be explored while setting up the right to palliative care as part of a partnership approach, mutual respect, and recognition of the sector's breadth of experience and knowledge.

14. Health and social care are less integrated than was hoped when the Public Bodies Act was passed in 2014. This has limited the potential for palliative care services to innovate, change and grow to better meet the needs of local populations and support the shift in care from acute to community settings. Some of these issues were exacerbated by the pandemic.

15. The right to palliative care offers an opportunity to address these concerns, but this will only be possible if there is a genuine and strong commitment to working with all sectors and partners including health and social care, the third and independent sectors, as well people who need palliative care and carers.

16. This will require strong leadership to implement this approach, alongside key learnings from IJBs, to achieve success. Crucially, this must also include the rectification of corporate governance and accountability issues which have been long-standing problems on IJBs, as described by, for example, Audit Scotland[83].

17. There is a strong need for closer collaboration between Local Authorities and NHS Boards, but until there is a shift towards truly integrated budgeting and genuine strategic partnership taking a whole system approach for Integration Authorities, challenges with delivering integrated care will remain. Addressing the current disconnects between community and hospital based care is as important as addressing those between health and social care.

18. The direct and indirect impact of the right to palliative care on NHS Scotland itself, from a structural, governance, people and sustainability perspective will need careful management and risk assessment from the outset of planning for and then delivering the right to palliative care.

[83] Audit Scotland: Integration Joint Boards Financial Analysis 2021-22: https://audit.scot/uploads/docs/report/2023/nr_230406_financial_analysis_ijbs.pdf

19. Addressing these issues will require transformational leadership with leaders who will maximise input and influence with delivery partners to achieve the change and success required.

Integrated and coordinated palliative care

20. A right to palliative care must move away from the focus on risk that hampers current palliative care delivery and commissioning, to one of enabling people to access the care and support that they need to lead a full life.

21. This principle should also apply when a person is assessed or reassessed for care as they move toward the end of life, and a focus on quality of life and supporting people to live as well as possible and meeting their wishes where possible.

22. Early intervention and planning are key to delivering person-centred care and support for those who are terminally ill and approaching the end of life. This should be at the heart of any care assessment process for the right to palliative care Minimum Service Standards, and reflected in care at home packages, including social care.

23. For care assessments and care coordination as part of the right to palliative care to deliver and implement a Minimum Service Standard, there is a need for a single point of contact with a single planning process (including IT system) and a single plan/pathway within a defined locality that can be tailored to each individual's needs. This must also link with other parts of the system including primary and secondary healthcare services, and social care, and the plans must be accessible by professionals supporting a terminally ill person, including unpaid carers.

24. Far too often, people have multiple care plans, or no care plan, and many different points of contact who are not coordinating with each other. This leads to considerable pressure on those receiving care. It results in stress and anguish for a person's carer who is left to try and navigate the systems. These existing data sharing issues must be addressed as a matter of urgency as part of designing and implementing a right to palliative care.

25. The right to palliative care should ensure that existing issues with delayed care assessments for palliative care, including social care packages, are addressed and streamlined; currently care packages are often rigid and inflexible and lead to patients waiting considerable lengths of time before being discharged from hospital.

26. Some patients may be discharged from hospital with the support of alternative services, such as urgent hospice care at home, which provide intense health and social care support for a short period of time until social care packages can be put in place. However, not every locality can access these services, and where they are available, they are frequently not commissioned to great enough capacity meaning that not everyone who needs to be supported can be.

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27. Many terminally ill people who are discharged from hospital may also be quickly readmitted because care needs remain unmet in the community. Even before the pandemic, Marie Curie was also aware of patients in communities who needed urgent care and were at risk of being admitted to hospital but faced significant waits for help. This has worsened considerably in the aftermath of the pandemic with extensive waiting lists across primary, secondary and social care. This is the worst possible scenario especially for patients with a short prognosis of only a few weeks or months, causing significant amounts of stress and discomfort, and in many cases, avoidable pain and agitation.

"Dealing with delays in getting my grandmother the appropriate level of care added to the distress of her family. She spent months in hospital, which could have been avoided if it was easier to navigate the health and social care system and my mother had been made aware of her rights as a carer.

"Constantly having to call to see if funding was in place to have my gran moved to appropriate care, dealing with her calling us confused and not knowing why she was there, these were all so difficult and added to the despair of watching her personality and memories vanish.

"Nobody would admit for months that her condition was as bad as we suspected it was, then once she was admitted to hospital as an emergency due to self-neglect all the control was taken away from my gran and the people who loved her.

"While we did eventually get her the care that she needed we had to fight for this, and months were wasted that we could have enjoyed with her while her sense of self was still somewhat intact, and she remembered who we all were. - Clare, Glasgow

Palliative care in hospitals

28. Over half a million people in Scotland will die in Scottish hospitals in the next twenty years, and millions of people with palliative care needs and approaching the end of life will be cared for in a hospital in the years and months before their death.

29. Public policy approaches in recent years emphasising care in community settings have led to a mistaken perception by some that any palliative and end of life care provided in a hospital setting represents a failure of the system or a 'problem'[84].

30. Palliative and end of life care takes place in hospitals daily, where people need and often choose to be. The issue with much of the palliative and end of life care in hospitals is not that it isn't taking place, but that it needs to be better supported and resourced. This could be achieved by stronger implementation of the National Early Warning Score (NEWS) in Scottish hospitals, which identifies acute physiological deterioration early. In the context of a right to palliative care, people should have the right to be considered if they are, or should be, on a palliative pathway alongside the NEWS score, and that the patient and family have a right to be involved in conversations with hospital teams about any escalation of treatment.

[84] Past, Present, and Future: Caring for those at the end of life in Scottish Hospitals

31. There is a recognition and understanding from Scottish Government to hospital wards that more needs to be done to support palliative care in hospital settings, which should be an embedded aspect of a Minimum Service Standard for palliative care.

32. This should include greater championing and signposting of patient advocacy services such as Citizens Advice Scotland Bureaux and Patient Advice and Support Service (PASS) for patients across all care settings, including hospitals.

Improving partnership working

33. The right to palliative care must ensure there is greater investment and collaboration with services such as urgent hospice care at home to support the delivery and implementation of a Minimum Service Standard. Marie Curie's services have been proven to support thousands of patients and reduce hospital bed days and admissions, while also supporting patient choice for place of care and death where possible.

34. Early involvement and collaboration with hospice care at home, for example, would enable greater service proactivity in supporting hospitals and emergency services by mapping local palliative care need. This would mitigate some crisis situations for both patients and families, and health and social care professionals.

35. For this to be carried out effectively, the range of services must reflect the potential needs of individual patients. At present, for example, 111 systems default to on call GPs or hospital admission when often what is required is a District Nurse/NHS Community team/hospice care at home. The result is a further need for referral and a subsequent delay in the individual receiving relevant care.

36. The Minium Service Standard set as the delivery mechanism for the right to palliative care must support processes which ensure care being provided reflects the patient's needs, including when these change from the deterioration of condition(s), and that support is delivered rapidly.

Patient records and plans

37. There is a need for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery for the right to palliative care. This is paramount for ensuring consistency in palliative care service design and delivery for those with a terminal illness and at end of life. Such services must be informed by robust, accurate and reliable data which supports an asset-based approach to providing appropriate support to terminally ill people.

38. One of the biggest challenges facing people who are diagnosed with a terminal illness is being able to access the care and support they need. A lot of people who miss out on some or all of the care they need is because they are not identified for a palliative approach and never have a chance to discuss with health and social

care practitioners or their family the kind of support they need, their wishes and how they would like to spend the time they have left.

39. We believe a palliative approach should be introduced as early as possible following a terminal diagnosis or very serious illness where the possibility of it progressing to a terminal condition is high.

40. 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[85]. A KIS is used to support the creation of a patient's Future Care Plan.

41. A Future Care Plan can allow patients to discuss treatments and care options, as well as preferences such as place of care and where a person would prefer to die. It also allows a social care and spiritual preferences and wishes to be captured and acted on, as well as help identify carers.

42. 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 preferred place of choice.

43. Currently, only 69% of people with a terminal illness have an electronic care plan in place when they die in Scotland; with those with terminal cancer more likely to have one than those with other conditions.

44. Every person diagnosed with a terminal illness should be given the opportunity to have and discuss a Future Care Plan, which can be read, updated and easily shared electronically by anyone responsible for that person's care, including social care staff and third sector palliative care providers.

45. We believe that a Future Care Plan should also consider wider public health factors which influence and impact end of life experience, including housing, caring, transport, and financial circumstances, as shown extensively by Dying in the Margins. This is particularly important for rural and island communities, given the extent to which end of life experience is dictated by these factors and the support available, rather than what a patient needs.

46. In Greater Glasgow and Clyde for example, Future Care Plans already consider a terminally ill person's housing circumstances, but staff find it difficult to ask questions about a person's financial circumstances without feeling intrusive. This highlights a training need to empower workforces, also enabling additional support to be signposted relating to housing, social security, and energy support for example.

47. The roll-out of the National Digital Platform is urgently needed to facilitate accessible, easy exchange of Future Care Plans between all care providers, with appropriate digital training for all workforces, including social care.

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

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48. Patients and carers, where appropriate, should also be able to access Future Care Plans and many more staff should have access rights to capture or amend Future Care Plans.

49. Both the lack of robust data about terminally ill people's care (captured by Future Care Plans), and streamlined access to it, has been a long-standing issue for health and social care professionals which can significantly impact the palliative social care and support terminally ill people receive. This must be an embedded aspect of the right to palliative care.

50. The right to palliative care must also facilitate complete data integration between national entities such as the NHS with third sector services such as Marie Curie, CHAS, Leuchie House, Erskine, and the End of Life Care Together partnership, which provide valuable services to people living with a terminal illness. Rural and island areas must be fully supported within this process to ensure an inclusive approach.

Palliative care education

"We had no training in personal or medical care, we were not equipped to deal with this on a practical or emotional level. We needed support for personal care, to know when to give food and fluids. To know how to safely move our loved one.

"We needed to feel that our loved one had pain medication and end of life drugs when required not when the Rapid Response team could get there. We needed better communication from NHS staff members and some compassion."- Family member who shared their experience with Marie Curie.

51. Training and education are vital to professional development, knowledge and experience building but many health and social care professionals and unpaid carers face significant challenges accessing and undertaking palliative and end of life care training and education. This can result in (early) referral opportunities being missed due to lack of knowledge, and terminally ill patients missing out on the care they need.

52. A Palliative and End of Life Care Education and Training Framework by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support health and social care professionals has been developed. But the impact of how workforces are performing against the framework's different skill levels is unknown due to inconsistent measurement, and also what structure is in place (if any) to ensure consistent training delivery. The Minimum Service Standards is an opportunity to embed these resources and empower and equip workforces with the skills and knowledge they need.

53. Currently, much of the social care workforce does not currently have palliative and end of life care training yet is expected to deliver care for terminally ill patients, often with complex needs, at home and in care homes.

54. Scottish Care's report, *Trees that Bend in the Wind* explores this issue in great depth, highlighting the extent to which protected time and specialist palliative care training is often very limited or non-existent.[86]

55. We believe that palliative and end life care training should be mandatory for all health and social care staff working with terminally ill people to ensure a Minimum Service Standard of palliative care.

56. Marie Curie strongly believes this must specifically include staff working in care homes, to recognise that care homes are settings where palliative care is delivered.

57. Resource is one of the main obstacles for being unable to release staff for palliative and end of life education and training, which has been exacerbated through Covid-19 by additional demands on social care, as well as primary and acute care.

58. There must be a flexible, ongoing palliative and end of life care education programme established which is embedded in the right to palliative care that reflects a blend of face-to-face and digital learning to provide continual training opportunities for everyone delivering palliative care including social care workforces and carers.

59. This is particularly important for rural and island workforce and carers whose access to resources is more limited.

60. Monitoring and evaluation of a right to palliative care must be robust to enable data gathering of examples of best practice, support local and national improvement priorities, but also to evidence changes which may be required as the right to palliative care evolves.

61. A professional development programme for commissioning and procurement of professionals working in social care must be considered as part of a right to palliative care, to empower them with skill sets appropriate to the needs of the right to palliative care. We believe an approach that draws parallels with the existing Promise Design Academy framework should be considered; the academy develops service design champions with design and coproduction skills.

62. We strongly suggest the introduction of scrutiny principles as part of Integration Authorities' duty to commission an agreed Minimum Service Standard of palliative care as the responsible body accountable for delivering consistently high standards of care.

63. But the approach to improvement, scrutiny and regulation, training and development must take a human rights-based approach and be aligned to existing public health systems and materials e.g. the Care Inspectorate Scotland, Healthcare Improvement Scotland, Public Health Scotland.

[86] https://scottishcare.org/wp-content/uploads/2019/11/Trees-that-Bend-in-the-Wind-Exploring-the-Experiences-of-Front-Line-Support-Workers-Delivering-Palliative-and-End-of-Life-Care.pdf

64. Scrutiny must, however, take an assets-based approach which is supportive to the teams who are delivering care, sometimes in incredibly challenging circumstances, and must acknowledge and celebrate good practice.

65. Key areas for improvement must also be identified, and where there are significant concerns for the safety and well being of service users, action plans must be in place to address these. Shared learning is an important aspect of this, and an opportunity for services to grow and develop. We believe this is vital in order to take a whole-system, public health approach to end of life experience which is consistent and can be measured effectively. It will also be more time effective.

Question 5: Are there any other comments you wish to make on the proposed Bill?



Project Diary: Margaret Mitchell

This is Stacey's story[87].

Stacey explored every avenue possible to treat her condition and extend her life. She lived with a rare hereditary genetic condition called Li-Fraumeni syndrome, which makes a person highly susceptible to developing cancer.

[87] Dying in the Margins: Media_1020538_smxx.pdf (gla.ac.uk)

She lived with her partner and her mother in a one-bedroom flat in inner city Glasgow. They supported her at home, as she tried to cope with her symptoms and manage her pain. This photograph below shows all the pills Stacey took over the course of a single day:



Stacey's photo-voice, Dying in the Margins

Her extensive medical regime to treat her cancer and her symptoms meant that Stacey needed to frequently travel back and forth to the hospital. This involved paying for a lot of taxi fares:

"I'm in the Health Centre for blood Monday, that's £20. Then to get injections Tuesday (£25). Then to see my surgeon on Thursday at the hospital (£20)."

It also meant having to go up and down the stairs in her tower block as the lifts often malfunctioned:

"I almost missed my appointment yesterday as the lifts weren't working again."

Space was a big issue for Stacey and her family. Her mum slept on the sofa bed which took up most of the living room, while her and her partner took the bedroom. But it was

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cramped with little privacy and there was not enough hot water for them all. Stacey was also trapped inside most of the time because of all the stairs. If she did make it outside, there were very few places to sit and no garden or parks to speak of:

"I'm in this overcrowded house and there are road works outside blasting away and I've two brain tumours."

Stacey and her partner made several attempts to move. These included using their initiative and lobbying their local MSP.

"I really need to move. I've been messaging the housing and phoning and phoning constantly trying to get out of here. My landlord is like 'Oh, there's no houses'."

After a year of trying unsuccessfully to move, they finally secured a two-bedroom ground-floor property. But Stacey had barely moved in when her symptoms were so bad that she was hospitalised and then moved into a hospice, where she spent her final few weeks of life.

Key points for question five:

- **Sustainable palliative care funding is vital to ensure the safe and efficient delivery of a right to palliative care, and the best patient health outcomes.**
- **National Commissioning and Procurement Structure Standards and Processes for ethical commissioning and procurement of palliative care services is a vital aspect of the implementation of a right to palliative care.**
- **Integration Authorities and Health Boards should take a collaborative, whole system approach to working with all partners in the community, with all sectors seen as equals in the strategic planning and commissioning of services, as well as their delivery.**

1. In 2022-23, people who were dying spent over 90% of their last months in community settings[88], and indeed, the majority of terminally ill people Marie Curie supports tell us they want to die at home. This trend will continue to increase over the coming decade, and by 2040, Marie Curie research has shown that two thirds of all deaths will take place in community settings; in people's own homes, care homes and hospices.

2. Marie Curie is the largest third sector provider of palliative care in Scotland, supporting almost 8,000 people in 2022-23. Our two hospices, and hospice care at home service in over 30 Local Authorities can be delivered in a number of models, some planned in advance, matched to need, and some responsive to patients' unscheduled care needs. Most of the people we support are in the advanced stage of a terminal illness, in our hospice care at home service this reflects 45% non malignant disease and 55% cancer, and in our two hospices, 8% non malignant disease and 92% cancer.

3. Over the past number of years, as costs have increased, there has been a significant decrease in the activity Marie Curie and other third sector palliative care

[88] PHS last six months spent in community settings 2022-23

providers can deliver. There is no standard approach across the country to determine price or service level and a disproportionate amount of time is spent debating this, rather than agreeing how the palliative care sector as a collective can best support the care of people who are dying.

4. An agreed approach to sustainable funding, with an agreed proportion of costs being carried by both parties, and with equity across the country, will release capacity in the system to remodel services to better align with the needs of the people.

5. In addition, the added value of Marie Curie and similar services, will be appreciated more fully (including online and telephone information and support services, bereavement services, research, service development, policy development and education). Marie Curie is committed to co-funding the services we deliver, and to work in partnership with our health and care colleagues.

6. A cost benefit analysis of Marie Curie services across the UK revealed that in 2019-20, the total costs of delivering our services was just under £99 million per year, while generating an estimated benefits value of around £470 million per year.

7. This means the total return on investment, including benefits to productivity and quality of life, in relation to total running costs estimated for all the analysed Marie Curie services taken together is 372%[89].

8. But Marie Curie's current funding arrangement see commissioned income cover less than 40% of our costs, meaning charitable fundraised income supports the delivery of the palliative care we provide to dying people, their families and carers.

9. Voluntary income has a role in partnership working, as part of charitable contributions to the whole-system, public health approach Marie Curie is committed to.

10. Voluntary income supports connection with communities, generating a sense of shared responsibility which has a role at some level in facing the collective challenges terminally ill people, their families and carers, the palliative care sector and National and Local Governments are experiencing.

11. Voluntary income drives value propositions for service delivery, enables innovation in service design, Increases measured risk capability, and embeds the need to focus on outcomes.

[89] The evaluation only addresses the impacts to which it has been possible to ascribe economic value. The term 'impact' is used to refer to all the results or consequences of using Marie Curie services for patients and their families or carers. This includes direct consequences on the use of alternative services (such as fewer hospital admissions), as well as indirect impacts such as less time taken off work by family or carers because of poor mental health due to the death of a loved one. However, 'impact' can also include consequences to which it is not possible, within the methodology used by the researchers at York University, to assign an economic value, such as being better informed about an illness, pain reduction, or experiencing lower anxiety. The purpose of Marie Curie's work, which we share with other hospices and charities supporting people with terminal illnesses and at the end of their lives - is these impacts described which have no intrinsic or calculable economic value. Any economic evaluation is therefore only ever going to provide a very partial account of the value of the range of services Marie Curie delivers.

12. However, Marie Curie is clear that such income should be adding value to core statutory funded palliative care services, not serving as the primary source of service income.

13. The hospice sector as a collective in Scotland is operating at a £16m deficit[90], which is not sustainable in the short, medium or longer term meaning people will continue to miss out on some or all of the palliative support they need. A sustainable funding solution is an integral, mechanical aspect of delivering a right to palliative care.

14. Many aspects of spending on the last year of life are unknown, including care from family and carers, social services, community nursing and core general practice[91]. In NHS Highland for example, of the spend that is known, the amount spent on people in the last year of life has remained much the same over the period 2017-18 to 2019-20, with £44 million being spent in 2019/20- 71% (£31 million) of that £44 million is spent on emergency admissions[92].

15. Bed occupancy in NHS Highland related to emergency admissions for people at the end of life has increased from 25.2% of all emergency beds in January 2016 to 29.7% in July 2022, while spending on GP out of hours services for people in the last year of life increased by 18%[93].

16. Hospice charitable service spending in NHS Highland has increased by 27% over the period 2017-18 to 2019-20 (in line with 23% increase of inpatient activity, and 124% increase in outpatient hospice activity)[94].

17. There has been a chronic underfunding of palliative care for decades, despite dying, death and bereavement being a universal experience. This has resulted in significant unmet palliative care need and services which are under acute pressure from increased demand, with decreasing resources to meet it.

18. We strongly believe that palliative care services commissioned through Integration Authorities, particularly those delivered by the third and independent sectors should be sustainably funded. Funding models should be outcomes focused and based on population needs, with a view to long term commitments that allow for innovation and change. Such funding models are vital to support third sector organisations commissioned to deliver services that meet the needs of terminally ill people including community-based palliative care services and hospices.

19. Sustainable palliative care funding is integral to the implementation of a right to palliative care and ensuring its longevity, so that terminally ill people have an end-

[90] Hospice UK: Hospices in Scotland face £16m deficit
[91] End of Life Care Together: Accounting for Value https://www.nhshighland.scot.nhs.uk/media/pg4ndbzy/supporting-end-of-life-care-in-nhs-highland-accounting-for-value-report.pdf
[92] End of Life Care Together: Accounting for Value https://www.nhshighland.scot.nhs.uk/media/pg4ndbzy/supporting-end-of-life-care-in-nhs-highland-accounting-for-value-report.pdf
[93] End of Life Care Together: Accounting for Value https://www.nhshighland.scot.nhs.uk/media/pg4ndbzy/supporting-end-of-life-care-in-nhs-highland-accounting-for-value-report.pdf
[94] End of Life Care Together: Accounting for Value https://www.nhshighland.scot.nhs.uk/media/pg4ndbzy/supporting-end-of-life-care-in-nhs-highland-accounting-for-value-report.pdf

of-life experience which reflects what is most important to them delivered by palliative, health and social care workforces which are fully equipped and empowered.

20. Sustainable funding is not only essential to supporting health outcomes and patient experience at the end of life, but would also alleviate acute system pressures on unscheduled care services in particular by supporting terminally ill people in their communities. Use of unscheduled care services is a direct result of palliative care needs being unable to be met in community settings, primarily due to workforce pressures, and carer burnout.

21. A rising demand for unscheduled care results in major clinical resource and financial pressures on the health and social care system, both in and out-of-hours. People in the last year of life are significant users of unscheduled care with nearly 500,000 service contacts across Scotland, meaning services must be available 24/7[95].

22. Hospice care delivered in community settings, including hospice care at home, 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)[96]. 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[97].

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

24. Eliminating inequality and inequity must be integral to the purpose of the right to palliative care, and the palliative care funding framework, to deliver palliative support which reflects each terminally ill person's needs. This will include multiple approaches to physical, emotional and spiritual hospice care, including trauma-informed care, which the framework must be resourced to appropriately support.

25. Marie Curie Scotland recognises the pressures of the current financial landscape for both hospice care providers, including hospice care at home, and service commissioners. But without urgent action, terminally ill people in Scotland will continue to die without some or all of the support they need.

26. A sustainable palliative care funding framework is integral to respecting, fulfilling and protecting each person's right to palliative care. It should ensure:

[95] 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
[96] 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
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i. Equitable access and delivery of hospice care and hospice care at home in Scotland wherever you are, and whatever your care needs and wishes through:
    - Recognition that these services are integral to the successful delivery of hospice care and hospice care at home in communities across Scotland.
    - Reflecting varying local population health needs and multi-morbidities.
    - A whole-system, public health approach which works with all hospice care and hospice care at home providers to ensure successful service

ii. Financial security and viability of hospice care and hospice at home providers across Scotland to enable them to deliver person-centred care through:
    - Ensuring a minimum of 50% statutory funding for independent hospice care providers, including hospice care at home.
    - Ensuring independent hospice care and hospice care at home providers are funded fairly, relative to NHS funded services, and to each other.
    - Ensuring parity of esteem and fair pay for all staff who are employed by hospice care and hospice care at home providers in the NHS, social care and third sector.

27. National Commissioning and Procurement Structure Standards and Processes for ethical commissioning and procurement of palliative care services is a vital aspect of the implementation of a right to palliative care.

28. This refreshed approach to commissioning and procurement of palliative care services would take a proactive and assets-based approach to allow it to be more reflective of specific local community needs with the ability to adapt quickly when those needs change.

29. However, it is vital that this approach also works to ensure that postcode lotteries do not emerge and that examples of good practice are shared, as well as commissioning outcomes and knowledge. This can be facilitated through the national perspective.

30. We believe conducting a comprehensive needs assessment of local populations, as well as identifying all community assets should be an essential approach to any commissioning model used by Integration Authorities as part of their duty to commission a Minimum Service Standard of Palliative Care to meet local population palliative needs.

31. Integration Authorities should take a collaborative, whole systems approach working with all partners in the community with all sectors seen as equals in the strategic planning and commissioning of services, as well as their delivery.

32. Lived experiences from communities around required local palliative care provision should also be incorporated into these discussions to maintain a human-rights and person-centred approach.

33. This should also encourage reference to a broader public health approach that focuses on improving individual wellbeing, community cohesion and population health whilst reducing social isolation and inequality.

34. By taking this collaborative approach, communication between all partners will improve leading to greater health and social care integration, and a transition away from silo working that is still evident in several areas, and results in disjointed services and poor care of terminally ill people.

35. The approach should also support the development of processes that maximise the impact of the collective resources and assets of stakeholders, shared decision making and integrated care provision where it is deemed that care needs would be better addressed and outcomes improved by doing so.

36. A large proportion of existing social care models and frameworks are also rigidly confined to time and task, meaning carers are unable to provide the full extent of care patients may require (usually more complex for those who are terminally ill and approaching the end of life) because they only have 15 minute slots per patient.

37. Lack of time can also significantly impact on Future Care Planning. Complex communications around a patient's health also means time and task models do not meet patients' needs, for example, emotional conversations about changes to a patient's condition, the need to move to a care home, or feelings of isolation or loneliness in a patient cannot take place in 15 minutes, especially if immediate care needs are also being addressed.

38. The right to palliative care is an opportunity to ensure this time constrained approach is replaced with one which has person-centred outcomes at the heart of its delivery. Palliative and end of life care services, such as those delivered by Marie Curie, often do not, and cannot, follow these constrained models of care.

Conclusion

It is clear a right to palliative care would improve the health outcomes of terminally ill, people, and their families with choice and dignity at the heart of shared decision-making between patient and all practitioners involved in a terminally ill person's end of life experience across specialist and generalist palliative care.

The Minimum Service Standards must be fully resourced, implemented, and measured to achieve the change they are intended to.

People with lived experience of dying, death and bereavement should be at the heart of design, delivery, and implementation of the Standards to ensure an equity-informed approach to respecting, protecting, and fulfilling each person's right to palliative care.

Key points which outline the rationale and resources required for Minimum Service Standards for palliative care:

1. Integration Authorities[98] should have a duty to ethically commission Minimum Service Standards of palliative care which meets their local population health needs, recognising that this will be different in each area.

2. Sustainable palliative care funding is vital to ensure the safe and efficient delivery of a right to palliative care, and the best patient health outcomes.

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

4. Marie Curie recommends the World Health Organisation (WHO) definition of palliative care be used to inform the scope of a palliative approach to a right to palliative care. Domains encompassed within the definition must be balanced depending on each individual's priorities and needs.

5. An intersectional lens must be applied to the right to palliative care, with trauma-informed care embedded in the Minimum Service Standards to ensure equity of support.

6. Minimum Service Standards for palliative care must be responsive to the nuances of 'place' of care and death for each individual, and ensure sufficient resource to deliver person-centred support which reflects patient choice.

7. Development of the right to palliative care should involve terminally ill people, their families, carers and all health and social care professionals who support terminally ill people, in accordance with the PANEL principles (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality).

8. Partnership working, mutual respect and recognition between organisations and individuals will be at the heart of delivering person-centred palliative care as part of a person's right, and Health Boards' and Integration Authorities' duty.

9. There is a need for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery for the right to palliative care.

10. Training in palliative care should be a mandatory requirement for all workforces supporting a terminally ill person, including care home staff and social care staff, with provision for unpaid carers.

This is a crucial opportunity to work towards a Scotland where dying, death and bereavement are talked about openly, people can plan and discuss their care wishes, and palliative care is accessible whoever and wherever you are.

[98] or any successor bodies to Integration authorities created by the National Care Service legislation or any future legislation. This applies throughout this document where Integration Authorities are discussed.

About Marie Curie

Marie Curie is the largest third sector provider of palliative care for adults in Scotland, supporting over 8,000 terminally ill people in 2022-23. Marie Curie delivers expert support and advice through its two Hospices in Glasgow and Edinburgh, and Hospice Care at Home Service across almost all Local Authorities.

Marie Curie's Information and Support services can be used by anyone affected by dying, death and bereavement for practical and clinical information, and emotional support. In Scotland 2022-23, our Information and Support services were used over 100,000 times.

Marie Curie's Companion at Home tackles social isolation and loneliness, and can continue for up to three months after a patient has died to ensure families and carers still receive the support they need.

Marie Curie is also the biggest charitable funder of palliative care research.

Marie Curie care and support across Scotland:
https://www.mariecurie.org.uk/policy/scotland-constituency-profiles

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