Marie Curie Response

Scottish Government – Human Rights Bill

***Key message*: death is a universal experience, yet access to and delivery of palliative and end of life care remains unequal and inequitable.**

***Key recommendation*: Marie Curie believes palliative and end of life care must be a Minimum Core Obligation (MCO) of:**

1. **The right to the highest attainable standard of physical and mental health (Article 12 of the International Covenant on Economic Social and Cultural Rights)**
2. **The Incorporation of the Convention on the Rights of Persons with Disabilities**

Everyone in Scotland must have the right to the support they need at the end of life, and the opportunity for an end of life experience which reflects what is most important to them.

This is Linda and Nicola's story.

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.

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.

You can see Linda's full digital story here.

Dying in the Margins examines barriers to, and experiences of, dying at home for terminally ill people, their families and carers living with financial hardship and deprivation in their own words and images through photo-voice and digital storytelling[1].

Linda and Nicola's story reflects a common experience. It highlights the multiple, cross-cutting issues that affect people's experience of end of life. Poverty led to Linda being unable to receive all of the palliative support she needed, or have the end of life experience she really wanted.

This experience should not be acceptable in Scotland; why palliative care must be included as a Minimum Core Obligation (MCO) under Article 12 of the International Covenant on Economic, Social and Cultural Rights, and the Incorporation of the Convention on the Rights of Persons with Disabilities.

Introduction to palliative and end of life care in Scotland

1. In 2022-23, there were almost 63,000 deaths registered in Scotland[2]; 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 (or another form of dementia), heart, liver or kidney disease, motor neurone disease and advanced cancer.

2. Palliative support also includes symptom management, and can be offered at any point after a terminal diagnosis.

3. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis. 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.

4. Palliative care can be provided in different settings, including in hospital, a hospice, care or nursing homes and a person's own home. Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:
    - managing physical symptoms such as pain
    - emotional, spiritual and psychological support
    - social care, including help with things like washing, dressing or eating
    - physical, emotional, spiritual and financial support for family and friends

5. 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, 10,000 more per year, by 2040, with over 85s accounting for 45% of all deaths[3].

6. The demographics of people with a terminal illness are also changing, as people are living longer with more complex conditions. People dying with multi-

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[1] Dying in the Margins is the first research study in Scotland, and UK to use visual methods to evidence circumstances of dying at home in financial hardship. The research was undertaken by University of Glasgow and Marie Curie, and funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation)

[2] NRS Vital Events Reference Table 2022-23

[3] 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)

morbidities (more than one terminal condition) will have increased by over 80% in the next 20 years[4].

7. 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.

8. Marie Curie has responded to questions in this consultation most relevant to end of life experience.

Question 2: What are your views on Scottish Government's proposal to allow dignity to be a key threshold for defining the content for MCOs?

9. We support the proposal to allow dignity to be a key threshold for defining content for MCOs and would be vital in shaping a palliative care MCO.

10. Everyone deserves a dignified end of life experience which reflects what's most important to them. Dignity is a fundamental aspect of human rights[5], and Marie Curie agrees with the Human Rights Consortium Scotland's consultation response that "many people across Scotland live everyday with violations to their fundamental human rights, and they are all too often powerless to do anything about it"[6].

11. Under Article 12.1 of the International Covenant on Economic, Social and Cultural Rights, 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"[7].

12. 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"[8].

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[4] 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)

[5] EU Charter of Fundamental Rights: Article 1, Human Dignity https://fra.europa.eu/en/eu-charter/article/1-human-dignity?page=2

[6] Human Rights Consortium Scotland response to the Scottish Government's "A Human Rights Bill for Scotland consultation"

[7] 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-Legislative-framework.pdf

[8] 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-Legislative-framework.pdf

13. 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.[9]

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

15. Development of the palliative care MCO 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)[10].

16. A palliative care MCO would contribute to ensuring delivery of Article 12 of the ICESCR, the right to the highest attainable standard of physical and mental health, in a dignified manner.

17. Future Care Planning should be considered as an integral part of delivering a palliative care MCO. Future Care Planning 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 and their support needs.

18. Future Care Planning 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[11].

19. 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[12].

20. Every person diagnosed with a terminal illness should be given the opportunity to discuss Future Care Planning, 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.

21. This will support a dignified death, through understanding what matters most to each terminally ill person, and what their current and future palliative care needs are.

22. Scotland has some of the most deprived areas in the UK, and Marie Curie research has shown that 8,200 people die in poverty at the end life every year in Scotland[13]. This equates to an average of one in four working age people,

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[9] 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-Legislative-framework.pdf

[10] https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

[11] https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC6917358/

[12] https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC6917358/

[13] Marie Curie and Loughborough University Centre for Research in Social Policy: Dying in Poverty

one in three in deprived areas such as Glasgow and Dundee, and one in eight pensioners.

23. **Dying in the Margins**[14] provides stark examples of undignified death which significantly violate the Right to Life, and Article 12 of the ICESCR.

24. The study evidences the acute challenges that terminally ill people experiencing financial hardship face, in accessing some or all of the palliative support they need for a dignified end of life experience. These include physical and mental health support, social security and adequate standard of living, aligned with the International Covenant on Economic Social and Cultural Rights.

25. The threshold of dignity for defining MCOs is vital in a palliative care context and would be crucial to a palliative care MCO.

26. Marie Curie also supports the proposal by the Human Rights Consortium Scotland that the Bill should include a purpose clause that includes dignity, universality and participation and other key human rights principles[15]. It will ensure a shared and consistent understanding and interpretation of rights in the Bill while also building a culture of human rights. This is vital in the context of access to, and delivery of, palliative care.

Question 4: What are your views on the proposed model of incorporation?

27. Marie Curie agrees with some of the core elements of Scottish Governments approach to the model of incorporation, namely that the rights should be reproduced in the Bill specific to devolved competencies in Scotland. Where there are both devolved and reserved elements, we support the Human Rights Consortium Scotland's call that specific attention should be paid to consider how adopt a maximalist approach to having as many rights as possible within the Bill[16]. In the context of terminal illness, particularly rights in the CRPD and ICESCR.

28. It is also vital that an integrated approach is taken to embedding rights of the International Covenant on Economic, Social and Cultural Rights and Convention on the Rights of Persons with Disabilities, in order to reflect the entirety of a person's end of life experience.

29. In the context of terminal illness, this means thinking about the following rights simultaneously:
    - right to adequate standard of living (including housing),
    - right to social security,
    - right to highest attainable standard of physical and mental health (from the ICESCR), in conjunction with the CRPD.

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[14] Dying in the Margins is the first research study in Scotland, and UK to use visual methods to evidence circumstances of dying at home in financial hardship. The research was undertaken by University of Glasgow and Marie Curie, and funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation)

[15] Human Rights Consortium Scotland response to the Scottish Government's "A Human Rights Bill for Scotland consultation" (p3)

[16] Human Rights Consortium Scotland response to the Scottish Government's "A Human Rights Bill for Scotland consultation" (p4)

30. 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.

31. 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.

32. Many of these inequalities have been exacerbated during the pandemic and could have led to considerably worse outcomes for patients, including poor quality of care and experience at the end of life.

33. Marie Curie and Loughborough University research found that 8,200 people die in poverty every year in Scotland, equating to one in four working age people in one in eight pensioners[17]. There were also clear overlap between the most deprived areas in Scotland and poverty at the end of life, yet these issues are often considered separately.

34. People with protected characteristics are most likely to experience poverty throughout their lives. 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.

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

36. 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[18].

37. All of these indicators can affect terminally ill people's experiences of dying (morbidity), death (mortality) and bereavement (wellbeing).

38. 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[19].

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[17] Marie Curie and Loughborough University Centre for Research in Social Policy: Dying in Poverty

[18] Public Health Scotland: Measuring health inequalities https://www.healthscotland.scot/health-inequalities/measuring-health-inequalities

[19] National Records of Scotland: Healthy Life Expectancy in Scotland, 2019-21 https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/life-expectancy/healthy-life-expectancy-in-scotland/2019-2021#:~:text=Key%20Findings,since%202014%2D2016%20for%20females.

39. This builds a strong case for a dedicated MCO for palliative care, which recognises the entirety of a person's end of life experience through cross-cutting rights in the ICESCR and CRPD.

40. Moreover, we believe that the model of incorporation should include **duty to have due regard** and a **duty to comply with** rights in the Bill, particularly ICESCR and CRPD, with timescales specified in the Bill.

41. The third sector plays a key role in integrated services but is not seen as an equal partner and is often not included in early conversations with existing Integration Authorities regarding the strategic planning and commissioning of palliative care services. This has often been our experience of supporting the development of palliative care services in various Health and Social Care Partnership areas.

42. 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. But 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.

43. 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 able to represent themselves to IJBs, thus do not actively engage us in consultation work or activity with existing IJBs. We believe that new ways of engaging with the third sector should be explored as part of a palliative care MCO within the Bill, so that the full breadth of the sector's experience and knowledge can be utilised.

Question 5: are there any rights in the equality treaties which you think should be treated differently?

44. We support the Human Rights Consortium Scotland's call for Scottish Government to transparently demonstrate that its proposed approach of only placing a procedural duty, and not duty to comply, on the special protection treaties goes as far as possible within devolution limits[20].

45. Marie Curie also believes the Bill must include a strong duty to comply on all CRPD rights, otherwise terminally ill people will not receive all of the support they need for an end of life experience which reflects what is most important to them.

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[20] Human Rights Consortium Scotland response to the Scottish Government's "A Human Rights Bill for Scotland consultation" (p7)

This is Donna's story from Dying in the Margins[21].

Donna, 56, has experienced multiple hardships throughout her life, financial insecurity being just one. She is a single parent with caring responsibilities. She has experienced a series of bereavements over the last decade, including the sudden death of her son.

"I don't think I could be hurt any more than I have been hurt."

Donna lives with multiple chronic conditions, some of which, like COPD which is terminal, she has had for many years, while others are new. Together, her conditions cause her a lot of pain and breathlessness and she has low energy:

"I struggle to leave the house, to get dressed." Because she is housebound much of the time, she struggles with isolation:

"I feel like a prisoner in my home. I really feel like that. Nobody to go and see, I just need to sit here, basically."

Because she has so many different conditions, Donna's care isn't joined up and she struggles to get doctors to sort out her medications and get on top of her symptoms. She spends a lot of her time seeing different doctors for her different illnesses, and going in and out of hospital, which she says she hates, "because sometimes I wonder whether I'm going to come back out again**."**

46. The decision not to place a duty of comply on the special protection treaties does not fully incorporate these treaties and would have a significant impact on terminally ill people's quality of life and mean they would not get all of the support they needed.

47. This should also be considered with specific rights of ICESCR, including adequate housing.

This is Stacey and Joost's story from Dying in the Margins[22]

Stacey, 38, was living with terminal cancer in Glasgow. Space was a big issue for Stacey and her family. In their original property, Stacey's mum slept on the sofa bed which took up most of the living room, while her and her partner, Joost, had the bedroom. It was 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:

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

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[21] Dying in the Margins is the first research study in Scotland, and UK to use visual methods to evidence circumstances of dying at home in financial hardship. The research was undertaken by University of Glasgow and Marie Curie, and funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation)

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Stacey and Joost made several attempts to move:

"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. However, it did not have ramps for wheelchair access, or specialist equipment.

Stacey had barely moved in when her symptoms became so acute that she was hospitalised and then moved into a hospice.

Stacey died in April 2023, and immediately following this, Joost was issued with an eviction notice by the Housing Association, and ordered to leave their home within two weeks of Stacey's death.

This was before Stacey's funeral had even taken place.

48. The treatment of Stacey and Joost was unacceptable, and meant that they did not get the palliative support which was right for them, which significantly impacted Stacey's end of life experience and Joost's experience of bereavement.

49. Marie Curie supports the Human Rights Consortium Scotland's calls that the substantive rights in CRPD must have both a duty to have due regard and the duty to comply. This is of particular relevance to dying people, their families and carers[23].

50. Without this improvement to the current Scottish Government proposals, Government will not be carrying out its commitment to implement the Human Rights Taskforce's recommendations nor will it deliver human rights for people represented in the CRPD, including those who are terminally ill.

51. These stories highlight the importance of an MCO for palliative care to ensure terminally ill people, their families and carers have a right to accessing and receiving sustainable palliative care as part of Article 12 of the ICESCR.

Question 13: how can participation be best embedded in the framework of the Bill?

52. The PANEL principles[24], with participation as their starting point, are the longstanding and widely accepted approach to implementing a human rights based approach in Scotland.

53. Person-centredness is at the heart of palliative care. The voice of lived experience is vital in shaping any health and social care service, including palliative care.

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[23] Human Rights Consortium Scotland response to the Scottish Government's "A Human Rights Bill for Scotland consultation" (p16)

[24] https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

54. We believe participation should be embedded throughout the Bill, including in its purpose, in reporting on implementation of the Bill. This must include people who are terminally ill, their families and carers.

55. Furthermore, Marie Curie believes participation should be a core principle within the Bill's purpose and at the centre of shaping a palliative care MCO.

56. Marie Curie, would, in a similar vein, urge the Scottish Government to fully ensure representation of lived experience of dying, death and bereavement in development and implementation of the National Care Service and the Scottish Government's upcoming Palliative Care Strategy.

57. Social care is an integral part of palliative and end of life care helping terminally ill people to live as well as possible right up until their death and supports an end of life experience which reflects what is most important to them. This includes being able to die in their place of choice, when possible, which is often at home or in a community setting.

58. Those living with a terminal condition are increasingly dependent on social care, particularly approaching the end of their lives, alongside primary care and palliative care services.

59. A palliative care MCO must ensure social care is a core consideration, and the approach to social care provision has person-centred outcomes at the heart of its delivery.

60. Many terminally ill people have complex, changing care needs, and the level of support required will change as conditions deteriorate. This must be acknowledged and reflected in service design and delivery of a palliative care MCO.

61. Marie Curie strongly recommends a review of existing social care models and frameworks as part of the early undertaking of a palliative care MCO.

62. Being able to provide integrated, person-centred care in the community for terminally ill people and those approaching the end of life also has the potential to create savings and efficiencies in other parts of the health and social care system, for example, reducing demand on out of hours and emergency hospital admissions, which currently cost NHS Scotland £190m each year for those in the last 12 months of life[25].

63. A palliative care MCO should ensure there is greater investment and collaboration in community partnerships in delivering social care and community-based palliative care, to improve terminally ill patient's outcomes.

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[25] 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

Questions 14-18: incorporating further rights and embedding equality

64. Marie Curie agrees that there should be an equality provision, and for LGBTQ+ and older people to be specifically named because of known issues in barriers to rights for these groups.

65. 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[26].

66. This evidences a clear violation of older people's rights, particularly Article 12 in the ICESCR; the right to the highest attainable standard of physical and mental health.

67. For some adults over 85, there is evidence which highlights a lack of discussion about preferences at the end of life, including place of 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.

68. 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 for to understand their end of life care options.

69. 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.

70. 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.

71. 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.

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[26] Marie Curie: Enough for Everyone, Challenging inequities in palliative care
https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/challenging-inequities-in-palliative-care.pdf

72. Scotland has an ageing population, and particularly high elderly populations in rural and remote areas of Scotland.

73. Marie Curie research has found that by 2040, the biggest increase in palliative care demand will be in over 85s[27], meaning a large proportion of future palliative care need is likely to be in rural and remote areas.

74. 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[28].

75. Marie Curie research has also found that up to two thirds of all deaths will take place in community settings; in people's own homes, care homes and hospices[29].

76. Geographic accessibility is a significant determinant on how easily terminally ill people, families and carers can physically reach a palliative care provider's location.

77. Research has shown geographical access to inpatient palliative care is associated with where people die, and patients living more than 10 minutes from inpatient care are less likely to die there[30].

78. More broadly, people living in rural areas are less likely to live within 15 minutes' drive of key public services, particularly those in remote rural areas[31].

79. More people (including older people) in rural areas will be dying at home, whether or not that is their preferred place of care and death because they cannot reach different care settings such as care homes, hospital or hospices. This places increased demand on community palliative care providers, including the social care workforce, and carers who already face significant challenges delivering palliative care in rural and remote settings.

80. It is therefore even more important that rural homes can also reflect access and installation of home adaptations to ensure a terminally ill person's home is fit for purpose to receive palliative support, and to die there, if that is their wish.

81. However, demand for accessible properties and home adaptations currently outweighs supply across Scotland, which is more acute in rural and remote localities. This generates further implications for bereaved families in remote and rural areas facing eviction from their property after the terminally ill person has died.

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[27] 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

[29] 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)

[30] 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*

[31] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

82. There are also intersectional transportation issues which restrict accessibility to palliative care including poor road conditions, lack of public transport, lack of volunteer drivers and lack of accessible vehicles. This can leave people reliant on expensive public transport.

83. These costs are exacerbated by the nature of living with a terminal illness. People may have multiple appointments, spread across several locations and dates with different specialists.

84. Choice at the end of life in rural and remote settings is further limited by poor access as palliative and end of life care needs cannot be as person-centred, instead needs are shaped by reduced access and limited availability of palliative care services.

85. These challenges result in significantly reduced opportunities for early palliative care interventions and poorer pain management for rural and remote (older) patients, resulting in a poorer quality end of life experience than someone in a more accessible part of Scotland could expect.

86. This highlights a violation of an (older) person's right to the highest attainable standard of physical and mental health.

87. In the context of experiences of LGBTQ+ terminally ill 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[32]. 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.

88. 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.

89. 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.

90. 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+.

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

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

92. While Marie Curie supports visibility of these two particular groups, we strongly believe that all terminally ill people must be given additional visibility in the Bill because of being particularly vulnerable to having their rights undermined by systems that do not meet their needs. It further highlights the case for a palliative care MCO.

Question 19: what is your view on who the duties in the Bill should apply to?

93. Marie Curie is the largest third sector provider of palliative care for adults in Scotland, working in partnership with specialist and generalist services, including social care, to ensure people receive the best possible palliative and end of life care.

94. Marie Curie upholds the human rights of every person affected by dying, death and bereavement that we support, and want to ensure everyone who is terminally ill in Scotland has the best end of life experience through a human-rights based, and whole-system approach to palliative care.

95. The duties in the Bill will act as a vital safeguard for terminally ill people to be able to access the support they need. We believe the duties should apply to all relevant devolved public bodies and to private bodies carrying out devolved public functions.

96. Everyone should expect their human rights to be respected, protected and fulfilled in both devolved and reserved competence. This is particularly critical for people living with a terminal illness and those close to them, and further highlights the case for a palliative care MCO.

Question 21: what is your view on the proposed duty to comply?

97. We agree that public and relevant private bodies should be given a duty to comply within the Bill and that this should include delivering MCOs. The duty to comply should also apply to the substantive rights within the CRPD.

98. Many terminally ill people miss out on some or all of the palliative support they need, as highlighted within the **Dying in the Margins**[33], and the subsequent impact this has on end of life experience. An MCO for palliative care would help remove these barriers to ensure terminally ill people can access and receive all of the palliative support they need, to the best possible standard.

99. **We strongly urge Scottish Government to introduce an MCO for palliative care**.

Question 27: what are your views on the most effective ways of supporting advocacy and/or advice services to help rights-holders realise their rights under the Bill?

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[33] Dying in the Margins is the first research study in Scotland, and UK to use visual methods to evidence circumstances of dying at home in financial hardship. The research was undertaken by University of Glasgow and Marie Curie, and funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation)

100. Advocacy is often considered in the context of justice, but it has an equal importance in the context of terminal illness which must be included in Marie Curie's proposal of an MCO for palliative care.

101. Evidence from Dying in the Margins, by University of Glasgow and Marie Curie, has found that there is insufficient independent advocacy for terminally ill people experiencing deprivation and financial hardship; meaning they are lost in health and social care, social security and housing systems and do not get the support they need either while they are dying, or after death.

102. This is true of all participants of Dying in the Margins, particularly showcased in Linda, Donna and Stacey & Joost's experiences detailed above. They all experienced injustice in accessing the palliative support they needed, and as such it significantly impacted their experience of end of life.

Question 39: what are your views on proposals to establish minimum core obligations through a participatory process?

103. Marie Curie agrees that MCOs should be developed through a participatory process and believes that this **should include the introduction of a new MCO for palliative care designed in participation with people with lived experience of dying, death and bereavement**.

104. In addition, Marie Curie believes that all relevant MCOs in social security, physical and mental health and adequate living should be designed with the participation of terminally ill people, their families and carers to ensure the MCOs can support the best possible end of life experience.

Question 40: what are your views on the proposals for a Human Rights Scheme?

105. Marie Curie supports the proposal to have a Human Rights Scheme, but believe that it must be developed following the participatory process outlined above.

106. In particular, the Scheme should include data collection on different aspects of terminal illness as a core marker, to better understand the experiences of people living with dying, death and bereavement.

107. Data capture and collection related to dying, death and bereavement has been historically poor, and the Human Rights Bill provides an opportunity to significantly improve this.

108. **A palliative care MCO strengthens the case for a for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery**.

109. 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.

110. 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.

111. 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 any carers.

112. 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[34].

113. 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[35].

114. 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 by anyone responsible for that person's care, including social care staff and third sector palliative care providers.

115. Both the lack of robust information about terminally ill people's care needs and wishes, and ability to access to any information which is available, have been long-standing issues for social and health care professionals which can significantly impact the palliative social care and support terminally ill people receive.

116. **The Bill provides the opportunity to rectify this issue including as an important element of the proposed palliative care MCO**.

About Marie Curie in Scotland

Marie Curie is the largest third sector provider of palliative and end of life care services in Scotland for adults. In 2022-23, we supported over 8,100 people.

Marie Curie have two Hospices in Scotland, one Glasgow and one in Edinburgh. As well our inpatient services, the hospices offer outpatient services for terminally ill people and in some cases their bereaved loved ones delivered by clinical staff, allied health professionals and counsellors. Clinicians from both hospices also offer expert palliative support to generalist and community health and social care staff.

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[34] https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC6917358/

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Marie Curie's Hospice Care at Home service is active in 31 of Scotland's 32 local authority areas. The exact Hospice Care at Home service Marie Curie provides differs by area but the key services we provide are:

- A "Managed Care" service where a clinical coordinator manages all aspects of a patients care to make sure they are fully supported at the end of life.
- A "Urgent Hospice Care at Home" service where a nurse or a social care assistant will respond to urgent calls for assistance.
- A "Sitting Service" where a nurse or a social care assistant will go to a terminally ill persons home and spend a block of time with them (often through the night) to provide care and provide respite for carers.
- A "Fasttrack" service where Marie Curie will provide comprehensive health and social care support to allow a terminally ill person to leave hospital without a care package from their local authority in place.

The Marie Curie Information and Support line can be called from anywhere in Scotland for practical or clinical information, and emotional support for someone living with a terminal illness, their carer or someone who has experienced a bereavement.

Marie Curie's Helper and companion volunteer service supports tackling the social isolation many terminally ill people feel after a diagnosis.

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

For further information:

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