Marie Curie

Care and support through terminal illness

Marie Curie Response

Scottish Government – Cancer Strategy

Introduction: Cancer and the current palliative end and of life care landscape

1. In 2020-21, there were over 63,000 deaths registered in Scotland[1]; around 90% of those (56,700) had a palliative care need. Palliative and end of life care supports people who have a terminal illness. By terminal illness, we mean a disease or condition which will likely result in the person's death. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.

2. 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
   - support for family and friends

3. 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[2].

4. The demographics of people with a terminal illness are also changing, as people are living longer with more complex and multiple conditions. Pre-pandemic, Marie Curie led research showed cancer deaths are projected to increase to almost 20,000 by 2040.

5. 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 care services, including social care, for terminally ill people with cancer and other terminal conditions with complex needs which will continue to increase.

6. We acknowledge the strategy's focus on prevention and early diagnosis of cancer to reflect increasing cancer survival rates in Scotland.

7. However, a wealth of existing evidence has demonstrated the benefits of the timely/early introduction of palliative care in cancer cases, including integration alongside active treatment when appropriate. Studies have shown that early access to palliative care in cancer cases 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 recommends palliative

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[1] NRS Vital Events Reference Table 2020-21

[2] 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)

care involvement in a patient's care within eight weeks of a diagnosis of advanced cancer.[3]

8. As a result of health and social care services being so stretched during the pandemic, and some treatments being completely paused, many people were not able to access the cancer support they needed to either diagnose or manage their condition, and presented to services much later, increasing the risk of their cancer becoming terminal.

9. Covid-19 has shown the distressing impact dying, death and bereavement can have on anyone at any time, and the importance of easily accessible integrated health and social care services, including palliative care, when they are needed most.

10. Long-standing issues with health and social care integration, care co-ordination and lack of sustained national and local investment in community palliative care services, as well as social care, have been exacerbated by the pandemic and in part due to a rapid shift towards community care. There has been a significant physical, emotional and financial impact on patients, their families and carers, and health and social care professionals which will be long-lasting for years to come.

11. The Scottish Government's Cancer Strategy must reflect care needs of terminally ill people living with cancer, in addition to its focus on prevention and early diagnosis, otherwise terminally ill people will continue to be at risk of dying without the support they need.

Question 1a-c: what are the most important aspects of the cancer journey you would like to see included in a long-term strategy?

12. Marie Curie strongly believes that the strategy must fully embody a parallel planning approach to cancer to cover all potential outcomes of a person's cancer journey. Parallel planning involves hoping for the best and planning for the worst, where palliative care and anticipatory care planning are carried out alongside plans for rehabilitation and recovery (where appropriate)[4].

13. Anticipatory Care Planning (ACP) allows patients and healthcare teams to discuss treatment and care options, as well as preferences of place of care and where a person would prefer to die. It also allows spiritual and social preferences to be captured, as well as help identify family carers.

14. Having an ACP 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.

15. Marie Curie led research shows that 69% of people in Scotland have a Key Information Summary (KIS) in place at the time of death, created on average 10 months before death[5]. Around 80% of people in Scotland with cancer have a KIS which is welcome

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[3] 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)

[4] Hudson, B et al Challenges to discussing care with people experiencing homelessness: a qualitative study BMJ Open

[5] Finucane. A et al: Electronic are coordination systems for people with advanced progressive illness: a mixed-methods evaluation in primary care. British Journal of General Practice https://bjgp.org/content/70/690/e20

progress in recent years. However, there needs to be continual progress especially around recording carer information.

16. Palliative care must be included at the heart of the longer-term strategy and prioritised in the short-term to manage a potential increase in demand in palliative care services. As a result of health and social care services being completely overwhelmed during the pandemic, and changes, delays or cancellations to treatment options such as chemotherapy and radiotherapy, there has been a greater risk of cancer diagnoses becoming terminal.

Question 2 – do you agree with 10-year high level strategy which will be underpinned by three-shorter term action plans?

17. Marie Curie supports the proposal of a 10-year strategy as this will allow necessary long-term workforce, financial and health and social care system planning which must include palliative and end of life care to ensure people living with terminal cancer get access to the support they need.

18. However, the 10-year strategy document and three-shorter term plans must be co-designed with all care providers including those providing palliative care, with lived experience at its core, and reflect a whole-system approach to ensure that milestones are being fully met through clear and specific key performance indicators (KPIs), that are regularly evaluated. This must also include future pandemic planning.

19. Such an approach will require the strategy to be underpinned by a strong evidence base, while enabling a response to any existing and emerging trends in cancer deaths as a result of changing external factors.

20. Marie Curie research has shown that if current trends continue, cancer-related deaths are expected to remain high, and alongside other terminal conditions such as dementia, are projected to be the dominant illnesses accounting for palliative care needs by 2040. Our research also estimates around 307,000 more people aged 65 and over will be living with a multi-morbidity (more than one condition) by 2040, over one million in total, meaning people could be dying from cancer plus another terminal condition.

21. Marie Curie research also projects that by 2040 two thirds of people will die in community settings, including people's own homes and care homes. They will require social care support, as well as community-based palliative care.

22. The cancer strategy must be able to support these complex needs to ensure that people can remain in community settings to receive palliative care if that is their choice and is possible, as well as receive the highest possible quality of care.

23. Having knowledge of local care trends, patterns and needs, as well as future projections of needs enables informed decisions to be made to ensure appropriate palliative care services can be provided for terminally ill people living with cancer. This must include continuous needs assessments of the national and local populations as well as a plan for future projections of need to inform strategic planning and service delivery.

Question 3- Do you agree with the vision; *'A compassionate and consistent cancer service, that provides improved support, outcomes and survival for people at risk of, and affected by, cancer in Scotland'.*

24. Marie Curie believes that the above vision must more explicitly include the health outcomes of people who are terminally ill living with cancer to ensure the strategy delivers the best physical, emotional and spiritual palliative support possible for an end of life experience that reflects what is most important to every individual.

25. This must include parallel planning to cover all potential outcomes of a person's cancer journey, not just survival, as the number of people dying from cancer and requiring a palliative approach continues to increase, and is expected to reach approximately 20,000 by 2040.

26. As highlighted in point 10, parallel planning involves hoping for the best and planning for the worst, where palliative care and anticipatory care planning are carried out alongside plans for rehabilitation and recovery (where appropriate)[6].

27. Marie Curie therefore suggests the vision should include specific reference to support for those dying of cancer and their families, as well as the welcome emphases on prevention and improving survival and outcomes.

Question 4- do you agree with the proposed aims?

28. Specific support for people living with a terminal cancer diagnosis is a clear omission in the current strategy aims, which must be rectified.

29. Marie Curie believes an additional aim of improving access to palliative care support (including physical, emotional and spiritual) for people living with terminal cancer must be specifically reflected in the aims.

30. As part of the 10-year strategy and three shorter work-plans, the aims need to be SMART and FAST (frequently discussed, ambitious, specific and transparent) with delivery milestones which are regularly evaluated and can be clearly measured to ensure progress stays on track.

31. Marie Curie supports the aim to reduce health inequalities; in palliative care (and more widely) this has been a long-standing consequence of decades of structural inequality across Scotland.

32. 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)[7]. Public Health Scotland also identifies morbidity (disease) as an indicator of health inequalities[8].

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

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[6] Hudson, B et al Challenges to discussing care with people experiencing homelessness: a qualitative study BMJ Open

[7] Long Term Monitoring of Health Inequalities; Scottish Government; March 2022

[8] Public Health Scotland; What are Health Inequalities?

34. Data has shown that premature mortality for those under 75, all-cause mortality (aged 15-44) and healthy life expectancy for males and females have all increased in terms of relative inequality over time since 2013[9].

35. Marie Curie research has shown that multi-morbidities (at least one terminal condition) are becoming the norm in Scotland and rising steeply with age. By 2040, the number of people who will die with multi-morbidities will increase by 82% to over 28,600, accounting for 43.5% of all deaths or nearly half (46%) of palliative care deaths.

36. This suggests there will be a greater level of complexity and different care needs in the coming years, compared to the current demands of terminally ill people, including those living with cancer. The shift from hospital to community settings as a result of Covid-19 has also given insight into what increased demand for palliative care support community settings could look like. Workforces must be well-equipped to manage this projected increase to ensure everyone receives the palliative care support which is right for them.

37. Those dying of two conditions often have more complex disease trajectories, as well as different and greater palliative care needs. There is a greater need for the coordination of relevant health and social care services to support this group especially.

38. A specific focus in the cancer strategy needs to be given to reviewing single disease health and social care models and incorporating multi-disease models, e.g. cancer, in conjunction with other terminal conditions such as dementia or heart diseases, to reflect increasing multi-morbidities in patients, while exploring sustainable funding solutions in parallel to ensure this is delivered fully.

39. The commitment to research in aim g) is welcome, and must include palliative care research as part of innovations in diagnosis and treatment.

Question 5- do you agree with the proposed principles?

40. Marie Curie supports the existing principles, but strongly believes that a whole-system approach and working with all care providers, including palliative care, to deliver the strategy must be more clearly articulated.

41. This would form part of the parallel planning approach to the strategy to ensure that people living with terminal cancer have access to all of the palliative care support they need.

42. Equally, empowering the voices of lived-experience must be at the heart of the strategy and included as an additional principle to a person-centred approach. This must include patients, their families and carers.

Question 6- do you agree with the proposed themes?

43. Similarly to the strategy's current aims and principles, palliative care is not clearly reflected in the strategy's proposed themes, and Marie Curie believes the principles should be SMART and FAST (frequently discussed, ambitious and transparent) to ensure that this is rectified. This will be discussed further in the some of the consultation's subsequent questions.

[9] Long Term Monitoring of Health Inequalities; Scottish Government; March 2022

Question 7- do you agree with the 'person-centred theme' areas of focus?

44. Marie Curie believes that a specific commitment to anticipatory care planning must be specifically included under person-centred care, to ensure that people living with terminal cancer are able to have their physical, emotional and spiritual care needs met, reflecting what is most important to them.

45. This is a simple extension of the strategy's proposed person-centred definition of partnerships between people diagnosed with cancer, their families and carers and those delivering healthcare services. But would ensure that terminally ill people living with cancer are included and fully supported.

46. Anticipatory Care Planning (ACP) allows patients and healthcare teams to discuss treatment and care options, as well as preferences of place of care and where a person would prefer to die. It also allows spiritual and social preferences to be captured, as well as help identify family carers.

47. Having an ACP 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.

Question 9- do you agree with the 'timely access to care' areas of focus?

48. Timely access to care is important, and this must include palliative and end of life care to ensure terminally ill people living with cancer can have the best possible end of life experience which reflects what is most important to them.

49. Marie Curie disagrees with the current proposed definition of timely access to care in the strategy, as this is not only applicable to identifying cancer as early as possible. While this is important, it must also be applied to timely access to palliative care.

50. One of the biggest challenges facing people who are diagnosed with a terminal illness, including cancer, is being able to access the care and support they need which can affect their quality of life.

51. 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.

52. 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. A palliative approach can be introduced while a person is still receiving curative treatment and can often complement that care, so it does not need to be a choice between approaches.

53. We know that many groups of people face difficulties accessing the care they need. The inverse care law applies in palliative care as it does in almost every other aspect

of life[10]. Ethnically diverse, deprived and rural communities are all far less likely to get the help they need as they approach the end of their lives[11].

54. We also know the majority of these groups are less likely to ask for help, and existing research has shown that this acts as a significant barrier for early identification and engagement with those who would benefit from palliative and end of life care[12].

55. The impact of people not getting the care they need when they die is devastating for them and can also have a significant effect in the wider health and social care system. There is a growing body of evidence that shows that investing in palliative care services in the community can increase efficiencies and reduce costs in the wider health and social care system, perhaps leading to significant savings[13].

56. The strategy must reflect all potential stages of a person's cancer journey, which includes palliative and end of life care. This must be given as equal an acknowledgement as prevention and early diagnosis, to support people living with cancer to have the best quality of life possible.

Question 10- do you agree with the proposed 'high quality care' areas of focus?

57. Marie Curie supports the high-quality care areas of focus, and reinforces the whole-system approach to the cancer strategy which must be embedded to achieve the best health outcomes for people living with cancer, including those with terminal cancer.

Question 11- do you agree with the proposed 'safe, effective treatments' areas of focus?

58. The safety of patients while planning and receiving treatment for cancer is paramount. Evidence has shown that unsafe care poses risk of significant harm to terminally ill patients receiving palliative care, primarily caused by lack of palliative care experience, under-resourcing (of health services) and poor care coordination, leading to worsened symptoms, serious injury, disrupted dying and a hastened death[14].

59. The impact of medical errors can also be significantly greater on terminally ill patients' physical and mental health due to being a vulnerable, frail population.[15]

60. Being able to identify and express what matters most to the individual at every evolving stage of the condition (anticipatory care planning) is fundamental and empowers all parties (patient/family and health and social care teams) to ensure the appropriate

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[10] https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf
[11] https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf
[12] Klop et al "https://www.ncbi.nlm.nih.gov/ pmc/articles/PMC5914070/" Palliative Care for Homeless People; a systematic review of the concerns, care needs and preferences and the barriers and facilitators for providing palliative care 2018
[13] 2.https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf
[14] Yardley, I et al Patient Safety in Palliative Care: A mixed-methods study of reports to a national database of serious incidents Palliative Medicine 2018
[15] Dietz, I et al Medical errors and patient safety in palliative care: a review of current literature Journal of Palliative Medicine 2010

support is aligned with care that reflects what is most important to the patient and their family when it matters most.

61. The need to ensure patient, family, carer and staff safety and wellbeing in community settings is paramount. Ensuring that all those in community settings, particularly in a person's own home, receive high quality and safe care when they are terminally ill and at the time of their death needs to be a priority for all those delivering services.

62. Marie Curie has long called for sustained national and local Government investment in community based care services, mandatory palliative and end of life care training for all health and social care professionals supporting terminally ill people and better practical, emotional and financial support for family carers both while they are caring for someone and after that person has died.

63. Without these investments, and reflection in the cancer strategy, more terminally ill people will be at risk of errors which could lead to a more distressing death.

Question 12- do you agree with the proposed 'quality of life' areas of focus?

64. Marie Curie supports the quality of life areas of focus, drawing particular attention to the role of palliative care support for terminally ill patients, their families and carers.

65. Our consultation response has taken an evidence-based approach to highlight the importance and necessity of full inclusion of palliative care in all aspects of the strategy's aims and principles (not just the 'quality of life' principle).

66. We believe this should be specifically referenced as physical, emotional and spiritual palliative support for patients, families and carers in the strategy to ensure individual care needs are fully met.

Question 13- do you agree with the 'data' areas of focus?

67. Marie Curie supports the data areas of focus but believe that the cancer strategy document must widen its scope in relation to types of technologies, to better incorporate the role of emerging and continually evolving technologies, including smart tech and Augmented Reality to further demonstrate forward thinking.

68. Integrating existing technologies to facilitate a more streamlined approach between palliative care, primary care and social care services is also an essential element of the cancer strategy to ensure terminally ill patients have the best quality of life (relating to question 12).

69. Marie Curie has long called for investment in innovations such as the National Digital Platform to enable all those supporting terminally illness patients, and patients themselves, to easily access digital records which can be updated by anyone responsible for that person's care.

70. But this is only the first stage: planning for the next generation of digital technologies and their role in palliative and end of life care provision in future is equally as important to ensure sustainability of these services and digital inclusion.

71. Scottish Government must note, however, that while digital technologies have been a lifeline to many throughout the pandemic there is still a high prevalence of digital exclusion. 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 has also led to high levels of isolation and loneliness during Covid-19.

72. This must be reflected in the cancer strategy to ensure that terminally ill people who are currently, or are at risk, of being digitally excluded are not disadvantaged and can still receive the palliative support they need from muti-disciplinary teams.

Question 14-15- suggestions for measuring improvements in cancer care and outcomes and health inequalities

73. Measuring and regularly evaluating the aims and principles of the cancer strategy is a crucial aspect of ensuring everyone living with cancer, including terminally ill people, are accessing and receiving all of the support they need.

74. As referenced throughout this consultation, Marie Curie strongly advocates for clearer commitments to palliative care support for terminally ill cancer patients, and their families and carers.

75. The primary and most impactful core outcome which should be included in the cancer strategy to reflect terminally ill people's care needs is improved access to the palliative support which is right for them.

76. We believe this should be measured by the completion and implementation of an anticipatory care plan for every terminally ill person living with cancer in Scotland, to ensure their care preferences and wishes are reflected (where that is possible) and are being met.

77. This would build on the progress already made that around 80% of people in Scotland already have an anticipatory care plan in place, but will require a whole-system approach in working with all care providers across all sectors to ensure all terminally ill people living with cancer get the support they need. It would also help reduce health inequalities, but greater targeted and proactive efforts will have to be taken to ensure everyone is given the opportunity to learn about and complete an ACP.

78. 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.

79. 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.

80. 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, including terminally ill people living in cancer.

81. Recent 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. There were also clear overlaps between the most deprived areas in Scotland and poverty at the end of life, yet these issues are often considered separately.

82. Protected characteristics groups in our society that are most likely to experience poverty throughout their lives, this increased risk persists to – and is magnified by – reaching the end of life, which when coupled with the current cost of living crisis, results in a vicious cycle that can become impossible to break.

83. Terminal illness is not the cause of 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.

84. It is vital that palliative and end of life support can be accessed by these communities; this includes, physical, emotional and financial support to help those affected by dying, death and bereavement to have an end of life experience which reflects what is most important to them.

85. As highlighted in points 30-32 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)[16]. Public Health Scotland also identifies morbidity (disease) as an indicator of health inequalities[17].

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

87. Data has shown that premature mortality for those under 75, all-cause mortality (aged 15-44) and healthy life expectancy for males and females have all increased in terms of relative inequality over time since 2013[18].

88. We strongly recommend health inequalities indicators are incorporated into the strategy's measurement and are regularly evaluated against how they are performing to improve health outcomes for people living with cancer, any stage, including end of life.

89. Finally, Marie Curie strongly recommends that Scotland's palliative care guidelines are considered to support measurement of the cancer strategy and particularly the health outcomes for people living with terminal cancer.

90. While the guidelines are not disease specific, it is essential that palliative care is considered alongside prevention and early diagnosis to support the health outcomes of people living with cancer at every stage of their illness, including end of life.

[16] Long Term Monitoring of Health Inequalities; Scottish Government; March 2022
[17] Public Health Scotland; What are Health Inequalities?
[18] Long Term Monitoring of Health Inequalities; Scottish Government; March 2022

About Marie Curie

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our volunteer led services.

We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK. In 2020/21, we provided care for over 9,000 people living with a terminal illness, as well as their families and carers across Scotland; our highest ever since the charity was established in 1948.

Our vision is for a better life for people living with a terminal illness, their families and carers. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

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