Marie Curie Response

Scottish Government – Health and Social Care for Older People Strategy

Introduction: older people 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 older people aged over 85s accounting for 45% of all deaths and the greatest demand for palliative care support[2].

4. The demographics of people with a terminal illness are also changing, as people are living longer into older age but with more complex and multiple conditions.

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 complex needs which will continue to increase.

6. As a result of health and social care services being so stretched during the pandemic, formal and informal support services which older people affected by dying, death and bereavement relied on were paused, and many were not able to access the support they needed to either diagnose or manage their terminal condition.

7. 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.

[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)

8. 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.

9. While we welcome the inclusion of palliative and end of life care in the Scottish Government's Health and Social Care Strategy for Older People, the strategy must take a whole system, public health approach which includes all providers of palliative support to older people- whether physical, emotional or spiritual- to ensure that the needs of older people affected by dying, death and bereavement are met.

Place and Wellbeing; examples of communities, voluntary/third sector and public sector organisations working together to improve older people's health and wellbeing and reduce any health inequalities which they experience

Case Study: Marie Curie Helper Service

Marie Curie Helper is a volunteer-led service which helps to tackle isolation and loneliness in older people by providing companionship. Marie Curie's trained volunteers are matched by personality and interests with a patient and their family, to provide emotional and non-clinical practical support for a minimum of three hours per week.

This includes:

- **Companionship and emotional support.** Helper volunteers can be there to listen and provide a friendly ear for someone to talk to
- **Practical help.** Helper volunteers can take patients to appointments or social events or help with small everyday tasks
- **A break for families and carers.** Carers may be able to take a short break while a Helper volunteer is there
- **Information on further support.** Volunteers can help patients and families look into other support and services available in their area, such as finding a gardener or cleaner to help around the home
- **Bereavement support.** Helper volunteers can also provide support to families for up to three months after bereavement

"Its kind of like having a friend- not like having a carer"- Faye.

The service provides a range of different language speakers, to ensure inclusivity of access and cultural sensitivities, helping to reduce risks of health inequality and inequity experienced by many.

In 2020-21, Marie Curie Helper supported over 165 households across Scotland. A clinical referral is not required, individuals can self-refer or a family member, friend or neighbour can refer them with permission.

The positive impact of Helper on patient, family, carer and volunteer wellbeing has been consistently evidenced over the years, supporting people affected by dying, death and bereavement to have an end of life experience which reflects what is most important to them.

Irene's journey to volunteering with Helper. *"Looking back on my employment, all the jobs I've had have involved caring in some way. It's something I've always enjoyed and found rewarding.*

"I've worked in pharmaceutical chemistry, the Royal Navy and as an infant teacher. After taking early retirement I worked in a charity shop and provided chaplaincy support. I wanted to continue caring for people which is important in my Christian faith. I saw a poster for the Marie Curie Helper service in the local supermarket and that was how I got started here.

"What I enjoy most about volunteering is meeting other people and hearing their stories. I learn about courage and the attitudes when faced with difficulties and admire others in difficult times. I want to feel useful and not become invisible in my older years. It's a satisfying experience and I also enjoy meeting all the other volunteers – these are some really amazing people.

"I've learnt a lot during my time volunteering, mainly counting my blessings. Everyone has hardships and worries and it keeps our own in perspective. Everyone likes to feel part of a community and the support I get as a volunteer is very rewarding and comforting and makes me feel a part of something bigger."

10. The strategy must fully maximise existing initiatives, such as Marie Curie Helper Service, to tackle isolation and loneliness in older people which has sharply risen during the pandemic across all communities in Scotland.

"Particularly during the pandemic, there's been an increasingly worrying impact on people's wellbeing, including social isolation, feelings of being overwhelmed, loneliness and increasing anxiety around diagnosis and prognosis. All of these factors greatly impact on the overall condition of our palliative patients and their loved ones." ***Marie Curie Nurse***

11. High levels of loneliness are caused by a variety of factors. Many people living with terminal health conditions are in older age groups, and their social networks have dwindled over the years as friends have died and family members have grown up and have lives of their own to lead[3].

"A lot is to do with people living longer than their friends and having no one from their age group to relate to." ***Marie Curie Nurse***

12. This has been further compounded by the social restrictions associated with covid-19, which have made it even harder for older people living with a terminal illness to spend time with others, particularly loved ones who don't live in the same household. In many cases, a surrogate social network will be formed by the health and social care professionals providing care, but these professionals are usually facing severe capacity pressures and often need to prioritise the person's symptoms and physical needs[4].

13. The impact of age on when, where and how people will die in Scotland is significant, especially in older people.

14. It can have a knock-on effect outcomes for older people who are terminally ill, including physical and mental health, housing and finance among others. This impacts access

[3] Experiences of Loneliness among people at the end of life; Marie Curie
[4] Experiences of Loneliness among people at the end of life; Marie Curie

to palliative and end of life care, exacerbating health inequality and inequity, meaning older people could be at risk of dying without the support they need.

15. Older people who have similar care needs as younger demographics have more unmet pain and less access to palliative care services than younger people with clearer diagnoses/illnesses.

16. Older people are much less likely to access and receive palliative care because their condition is associated with normal process of dying. For some over 85, the terminal nature of their condition was hidden from them, and there was evidence of a lack of discussion about preferences around end of life care, including place of death. This was evidenced by of a lack of Anticipatory Care Planning in these groups despite older people often have greater information needs than younger people with clearer illnesses.

17. Some older people are not able to access information due to poor eyesight and hearing, the amount of information given, as well as information using overly medicalised language. This makes it difficult for some older people to understand their situation and options open to them.

18. Even when death is expected referrals to palliative care are not always considered. Physicians are less likely to refer people over the age of 85 dying from terminal conditions. The reason being that physicians believe that the older a patient is the more likely that their needs are being met.

19. When community palliative care referrals are made, delivery of them can be difficult. It also points to no clear reason for this. It suggests that this may because services are prioritised for some younger age groups, or because of communication issues between different care settings.

20. Frailty is a complex, multidimensional problem associated with decline towards dependence and death[5]. The research particularly highlighted issues surrounding frail older people and how they were less likely than all other age groups and conditions to be accessing palliative care[6].

21. Frail older people often die without a defined single terminal illness, but they would still benefit from palliative care. However, they often do not have access to palliative care, palliative approaches and a 'specialist' who can negotiate services, such as Clinical Nurse Specialists.

22. It is vital that this inequality is addressed as part of the strategy, as by 2040, the biggest increase in demand for palliative services is projected to be in those aged over 85[7].

[5] Improving the identification and management of frailty, NHS Healthcare Improvement Scotland, 2013

[6] Why do older people get less palliative care than younger people?, European Journal of Palliative Care, 2016

[7] The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision Authors: Anne M. Finucane, Anna E. Bone, Catherine J. Evans, Barbara Gomes, Richard Meade, Irene J. Higginson and Scott A. Murray

Place and Wellbeing; advice and support needed to help make decisions about health, care and treatment?

23. Marie Curie strongly believes that palliative care must be incorporated into all priority areas of the strategy, not just 'dignity and respect at end of life' to embody a parallel planning approach to a terminally ill person's care and cover all potential outcomes of their journey.

24. 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)[8].

25. 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.

26. Having an ACP in place can reduce the amount of time an older 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.

27. 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[9]. Around 80% of people in Scotland with cancer have a KIS which is welcome progress in recent years. However, there needs to be continual progress for terminally ill people living with other conditions, including organ failure, and also recording carer information.

What kind of people or organisations could help? How could local organisations and places help?

28. Marie Curie strongly believes the strategy is an opportunity which must be taken to embed a cross-community approach which integrates existing initiatives to achieve the best health outcomes for older people living with a terminal illness, their families and carers.

29. Death and bereavement are still taboo subjects in Scotland and across the UK, and have been brought to the forefront during the pandemic but not by choice for thousands of people across Scotland.

30. Scottish Government must evidence transformative leadership through the strategy to encourage more open conversations about dying, death and bereavement and how this can support community connectivity.

31. This includes communicating the benefits and roles of hospices as community assets, where (older) patients can receive inpatient and outpatient treatment to support their terminal condition and be discharged to return home again where that is possible and is their choice.

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

[9] 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

32. Hospice services can support older people with physical, emotional and spiritual support as part of their palliative care. Marie Curie strongly believes that hospices should be considered equally as community hubs, where appropriate, alongside libraries, leisure and sport centres that the strategy mentions to help older people living with a terminal condition get all of the support they need to live and die well.

Case Study- Marie Curie Hospices

Marie Curie has two hospices in Glasgow and Edinburgh, with outpatient and day therapy treatment options, to compliment the palliative support an older person can receive.

Our day therapies help people manage their conditions and improve their quality of life. They include outpatient specialist palliative care, complementary therapies, health advice, creative activities and emotional support sessions. The Glasgow Hospice also offers bereavement support to families, including children (some of these activities are currently on hold due to Covid-19, which we hope to return to in the near future).

"In Marie Curie day hospice, the thing that everybody reports they miss so much (during Covid-19), is the company and the friendships they develop. They all say the same thing. It was the highlight of their week. It was what they looked forward to because they were with people who understood exactly what they're going through. And so many genuine friendships were developed. The social support they got was so valuable." ***Marie Curie Allied Health Professional***

Mental health and wellbeing

33. Mental health issues can be very apparent for many people living with a terminal illness, but can often go untreated and unsupported highlighting significant health inequalities and inequities. People can often develop mental health issues as a result of their terminal illness diagnosis.

34. There are many people with severe mental health conditions, such as bipolar affective disorder and schizophrenia approaching the end of life who are not getting the care they need.

35. Carers for people living with a terminal illness can be in a very vulnerable position and highly exposed to psychological distress, both during caregiving and following the death of a loved one, which can go unsupported.

36. There is very little research in Scotland, and the UK, to show how many people with severe mental health issues need palliative care, and how mental health needs are supported for people who are diagnosed with a terminal illness.

37. For people living with terminal illness depression can occur anytime such as following diagnosis, as their disease advances and pain increases, or as their independence becomes more limited. It is more likely if a person experiences more symptoms of their disease, such as swallowing difficulties, sickness or bladder and bowel problems.

38. At Marie Curie many people we support experience anxiety which can lead to varied reactions such as insomnia, restlessness, being agitated, sweating, heart palpitations, panic, worry and tension.

39. The fear of dying often creates anxiety and can lead to other mental health issues. Left unsupported this can have serious implications. Not only causing a detrimental impact on the quality of life a person has before they die, it can also see their condition worsen. It can even lead to suicide.

40. The strategy must recognise the range of support for older people which needs to be available. This can include access to psychiatrists and counsellors or other mental health practitioners, as well as support groups, and suitable medication to help with conditions such as depression or sleep deprivation.

41. It is also vital to consider how palliative care might support someone approaching the end of life with severe mental health conditions such as schizophrenia, bi-polar disorder or clinical depression. This could be their main condition or alongside another physical condition.

42. There is a lack of data available, however, to show how many people with severe mental health issues need palliative care.

43. But, we know that people with severe mental disorders tend to die earlier on average than the general population. The majority of these deaths are due to chronic physical medical conditions such as cardiovascular, respiratory and infectious diseases. Existing psychiatric symptoms can be made worse by a physical illness.

44. A study in Dutch mental health facilities in 2016 found that only thirty-six percent of nurses had experience with providing palliative care to psychiatric patients with physical comorbidities. It found that little attention for palliative care within mental health facilities was a problem and that the provision of palliative care for psychiatric patients needs to be improved[10].

45. Bereavement and grief can also significantly impact mental health and wellbeing, especially while caring for someone with a terminal illness, and after they have died. The pandemic has shown the distressing impact dying, death and bereavement can have on anyone at any time.

46. Necessary Covid-19 restrictions significantly impacted how people could grieve, and has resulted in more complicated grief in many cases, due to being unable to celebrate the life of a loved-one, friend or neighbour through usual traditions and cultures.

47. People's experiences of bereavement during the pandemic have also varied massively on the circumstances of loss; whether Covid-19, long-term illness, age, suicide or experiencing multiple losses in different contexts, such as loss of community support and relationships.

48. The strategy must include bereavement support for older people and their carers which is trauma informed, and reflects the complicated grief people have experienced throughout the pandemic to ensure mental health and wellbeing is fully supported.

49. Marie Curie has been closely supporting the **UK Commission on Bereavement** (UKCB), an independent commission established to explore issues and make recommendations on how better to support bereaved people across Scotland and the four nations. The UKCB has taken evidence from individuals, professionals and

[10] https://www.ncbi.nlm.nih.gov/pubmed/27530547

organisations affected by bereavement in 2021, and will publish its findings in September 2022.

50. In recognition of the importance of the UKCB's work and implications for longer-term bereavement support needs in Scotland, we believe national conversations should take place, led by Scottish Government. This should also be reflected in the strategy.

Housing, adaptions and equipment

51. Many terminally ill people, including those supported by Marie Curie, prefer to receive palliative care and die at home where that is possible. In 2020-21, over 90% of the last six months of life of those who died was spent in community settings[11].

52. But terminally ill people often face significant barriers getting the equipment and home adaptations they need, particularly when transitioning between care settings, such as hospital to home. This can often lead to the person's discharge being delayed, which means they may not get to die in their preferred place of choice.

53. Covid-19 has seen a marked shift of palliative care into the community and further into people's own homes. It is vital to understand how suitable a home is for that care to be delivered for those living with a terminal illness and coming to the end of their life. There are a range of important issues to be considered:

    a. Home accessibility and provision of equipment – i.e. cleanliness, space, ramps, handrails, walk-in showers, hospital beds, etc
    b. Home Infrastructure – i.e. insulation, central heating, dampness and mould
    c. Income – i.e. ability to afford gas/electric bills (fuel poverty)
    d. Service provision – i.e. repairs, lack of services, slow service response
    e. Demographic factors – i.e. age, poverty, gender, location

54. Findings from a survey of some Marie Curie staff found that housing experiences of terminally ill patients has largely remained the same during Covid-19 encompassing the above issues, but 20% of respondents reported a worsening of circumstances.

> *I had a patient in their own house where the bath and shower were upstairs. They struggled to walk upstairs, and had to stop half way up because they were so short of breath. The shower was really inaccessible as the patient had to step into it. It only had one plastic chair to sit on and no room for anyone else to help because the shower was so small. When the patient could no longer walk upstairs, they were told that because there was a toilet and sink downstairs – even though this was too small to fit a wheelchair inside – that they were not eligible for a stair lift. They didn't have any aids.* **Marie Curie Nurse**

55. These reports indicate that many vulnerable and older people's homes do not have the adaptations they need, and some that do are only as a result of being paid for by the resident. This may not be an option for many, and are issues which will also be faced by people living with a terminal illness.

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56. In a survey of some Marie Curie Nursing Service staff across Scotland, almost half of the respondents said they had visited a patient at home in the last 12 months which had not been suitable to support them and their condition because of a lack of adaptions and accessibility issues.

57. Marie Curie Nursing staff also reported the following barriers as the most common to patients getting adaptions installed in their homes:
    a. Issues with Local Authorities/Social Care
    b. Patients are unaware of what they are entitled to, or how to start the process
    c. Delays with care and repair services
    d. Financial issues such as patients being unable to afford adaptions
    e. Patients/families unwilling to get adaptions

58. Ensuring terminally ill people get the adaptations they need in their home as quickly as possible is essential in ensuring they can be as independent as possible and enjoy as a high quality of life as possible in the time they have left. This must be reflected in the strategy.

Health and social care services for older people

59. The health and social care system is still less integrated than was intended when the Public Bodies Act was passed meaning older people living with a terminal illness cannot access of all of the palliative support they need.

60. 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 Integration Authorities regarding the strategic planning and commissioning of palliative care services.

61. 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. The third sector has the expertise, knowledge and skills that should be engaged with far sooner in commissioning and planning processes of Integration Authorities.

62. The pandemic has exacerbated long-standing challenges with health and social care integration, care coordination and workforce recruitment and retention for older people living with a terminal illness, their families and carers.

63. 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. 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.

64. The strategy must take a whole-system, public health approach which works with all providers of health and social care, including palliative care, to ensure everyone has access to and gets the physical, emotional and spiritual support they need for an end of life experience which reflects what is most important to them.

65. However, the strategy must also consider the implications of the National Care Service (NCS), as responsibility for social care is shifting from Local Authorities to central government. There is a risk the NCS will increase the integration gap between health

and social care, highlighting the importance of a whole-system approach which must be mirrored and implemented in the strategy.

Anticipatory Care Planning and Integrated Planned Care

66. Marie Curie strongly believes that palliative care must be incorporated into all priority areas of the strategy, not just 'dignity and respect at end of life' to embody a parallel planning approach to a terminally ill person's care.

67. 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)[12].

68. 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.

69. Having an ACP in place can reduce the amount of time an older 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.

70. 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[13]. Around 80% of people in Scotland with cancer have a KIS which is welcome progress in recent years. However, there needs to be continual progress for terminally ill people living with other conditions, including organ failure, and also recording carer information.

71. Volunteers are an incredibly valuable support to terminally ill older people, their families and carers as well as other vulnerable groups affected by terminal illness, and also to health and social care professionals.

72. The strategy must champion palliative care training and empowerment of volunteers to help bridge statutory and non-statutory support while acting as an early warning system to health and social care teams as needs of those affected by terminal illness change. This should be proportionate and monitored closely to ensure volunteers are fully supported to deliver this if they choose.

Minority Ethnic Groups and Health Inequalities and Inequities

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

74. 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

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

[13] 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

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.

75. 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.

76. 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[14]. 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[15].

77. 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[16].

78. 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[17].

79. Marie Curie research has shown that if current trends continue, people will continue to live longer into older age but with more complex conditions. Cancer-related deaths are expected to remain high, and other terminal conditions such as dementia, are projected to be the dominant illnesses accounting for palliative care needs by 2040; dementia deaths increasing by 185%[18].

80. 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 more than one terminal condition. Older people aged over 85s will account for 45% of all deaths and the greatest demand for palliative care support[19].

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[14] https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf

[15] https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf

[16] 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

[17] 2.https://www.mariecurie.org.uk/ globalassets/media/documents/policy/ campaigns/equity-palliative-care-ukreport-full-lse.pdf

[18] 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

[19] 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

81. 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.

82. 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.

83. A specific focus in the strategy needs to be given to reviewing single disease health and social care models and incorporating multi-disease models to reflect increasing multi-morbidities in older people, while exploring sustainable funding solutions in parallel to ensure this is delivered fully.

84. 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 older people living with or affected by terminal illness.

85. The strategy must also acknowledge that the definition of 'older people' will be different across Scotland, given some areas experience more acute health inequalities, poverty and deprivation than others leading to shorter life expectancy.

86. The Scottish Index of Multiple Deprivation (SIMD) for 2020 highlighted the Glasgow area as making up the majority of the most deprived 20%, 10% and 5% areas in Scotland[20]. Healthy life expectancy in the most deprived areas of Scotland (including Glasgow), was more than 24 years lower than in the least deprived areas for both men and women, and in the most deprived areas men and women spent more than a third of their life in poor health[21].

87. For many of the 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.

88. Recent Marie Curie and Loughborough University research found that one in eight pensioners die in poverty at the end of life every year in Scotland, and one in four working age people[22].

89. 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.

90. 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.

[20] Scottish Index of Multiple Deprivation 2020

[21] National Records of Scotland; Healthy Life Expectancy 2018-20

[22] h420-dying-in-poverty-scotland-4th-pp.pdf (mariecurie.org.uk)

Palliative and End of Life Care and Planned Health Care and Reviews (responses to these sections have been combined)

91. 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

92. The importance and value of a palliative approach for older people living with a terminal condition has been demonstrated throughout this consultation and we welcome the inclusion of a *dignity at the end of life principle* in the strategy.

93. 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 older people who are terminally ill.

94. This must include continuous needs assessments and equality impact assessments of the national and local populations as well as a plan for future projections of need to inform strategic planning and service delivery.

95. Anticipatory care planning (ACP) is vital to supporting this, to ensure that older people living with a terminal condition are able to have their physical, emotional and spiritual care needs met, reflecting what is most important to them.

96. 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.

97. 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.

98. ACPs can also support integrated planned care for older people. But in order to effectively implement ACPs across Scotland, there must be much stronger health and social care integration and care coordination. These have been long-standing issues exacerbated by Covid-19 and are at the core of some older people not being able to access some or all of the palliative support they need.

99. Maximising existing data and technology integration to facilitate a more streamlined approach between palliative care, primary care and social care services is an essential element of this and should be reflected in the strategy to ensure older terminally ill patients have the best quality of life possibly.

100. 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.

101. 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.

102. 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.

103. This must be reflected in the 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.

Integrated unscheduled care

104. As terminally ill people reach the end of life, their reliance on unscheduled care can increase.

105. Marie Curie research has shown that demographic factors associated with more unscheduled care included older age, social deprivation, living in own home, and dying of cancer, as well as those with multiple health conditions. Public expectations, instructions to seek urgent care for suspected strokes or heart attacks, and less support in the community at weekends and overnight were also factors[23].

106. The research also showed people with cancer had on average more unscheduled hospital admissions than people with non-cancer diagnoses and the highest per patient costs. Older people who died with frailty were most likely to have unscheduled care managed fully in the community and had the lowest overall NHS costs[24].

107. Many people in their last year of life call on emergency services, especially if the GP practice has not started an anticipatory care plan and sent a summary to all out-of-hours services.

108. Rising demand for unscheduled care results in major clinical resource and financial pressures on the Scottish healthcare 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. People used all unscheduled care services increasingly as death approached, with 34.2% of use in the last month of life. During that final month, there was a disproportionate rise in primary care out-of-hours workload[25].

109. About 90% of these people had been living with significant health concerns and terminal conditions but did not have any palliative care needs addressed reliably. We also know that people with cancer were more likely to contact NHS 24 or primary care

[23] 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;0:e041888

[24] 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;0:e041888

[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;0:e041888

out-of-hours services and have hospital admissions and people with organ failure were the most likely group to call for an ambulance[26].

110. The total cost of unscheduled NHS care in Scotland for people in their last year of life was nearly £190 million, of which only 3.9% was spent on primary care out-of-hours services. The average cost of unscheduled care per patient in the last year of life were greatest for those with cancer (£4,083), followed by organ failure (£3,429), and frailty (£2,654)[27].

111. The total cost of unscheduled care used by those in the most deprived communities in Scotland was almost double the least deprived due to the larger numbers of people dying in this group and their higher use of secondary care services.

112. The conclusions from the research are clear; improving the ability of unscheduled primary care services to manage people in the community can potentially to reduce hospital admissions and overall costs. This has the potential to be highly cost-effective as well as supporting people's choice to remain at home towards the end of life, where appropriate.

113. The strategy must reflect the palliative care needs of older people who require unscheduled care, especially as much of this is delivered in community settings; and by 2040, two thirds of all deaths are projected to take place in people's homes, care homes and hospices.

Additional points for the health and social care strategy for older people

Measurement

114. The strategy's 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.

115. Equally, empowering the voices of lived-experience must be at the heart of the strategy and included as an additional principle. This must include patients, their families and carers.

116. Measuring and regularly evaluating the aims and principles of the strategy is a crucial aspect of ensuring older terminally ill people are accessing and receiving all of the support they need.

117. Measurement and evaluation processes are clearly absent from the strategy's current draft.

118. The strategy 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.

[26] 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;0:e041888

[27] 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;0:e041888

119. 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 deaths in older people as a result of changing external factors.

120. As referenced throughout this consultation, Marie Curie strongly advocates for clearer commitments to palliative care support for older terminally ill patients, and their families and carers in all aspects of the strategy.

121. One of the primary and most impactful core outcomes which should be included in the strategy to reflect older terminally ill people's care needs is improved access to the palliative support which is right for them.

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

123. 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.

124. 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 older people living with a terminal condition.

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

Gender and palliative care

126. There is a significant gap in gender and palliative care research in, but also internationally. However, based on existing international evidence, while we know that over half of all people would prefer to die at home[28], for many women this is often not possible or achieved. Social norms have dictated a society where it is women who are the natural caregivers and many even feel it is their duty when it comes to providing care[29].

127. Nonetheless, many women express fears around feeling like a burden if they themselves need care from family and loved ones[30]. In fact, we see more women receiving care and support from healthcare professionals and specialists rather than unpaid carers[31].

128. The fact that women have longer life expectancy and are more likely to outlive their partner (in a heteronormative relationship) into older age, reinforces this trend. Additionally, those who have been carers (of which the majority are women), are less

[28] Hoare, S. et al., 2015. Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. PLOS ONE, 10(11)
[29] Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. BMC Palliative Care
[30] IBid
[31] IBid

likely to want to die at home[32]. This is assumed to be due to a greater understanding of the reality of caring for someone at home. We therefore see more women dying in other settings such as hospitals, care homes, hospices and specialist palliative care settings[33].

129. Existing evidence has also shown that mental health is a highly gendered issue, with depression twice as prevalent amongst women, particularly women on low-income[34].

130. There is also significantly greater impact on women around social care, as women are the majority of social care service users, the majority of the underpaid workforce, and the majority of unpaid carers[35].

131. The strategy must show stronger recognition and understanding of the gendered dimensions which impact older people's access and receipt of health and social care, including palliative care, as a lack of gendered policy responses means existing inequalities are repeated and reinforced[36].

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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Marie Curie
Care and support through terminal illness

[32] Gott, M., Morgan, T., Williams, L., 2020. Gender and Palliative Care: A Call to Arms. SAGE Publications
[33] IBid
[34] Engender: Call for Ideas for the National Planning Framework; consultation response
[35] Engender (2020) Submission of evidence to the Scottish Parliament Health and Sport Committee on social care
[36] Engender: Call for Ideas for the National Planning Framework; consultation response