Marie Curie Response

Scottish Parliament Health, Social Care and Sport Committee- Inquiry into Health Inequalities

Current palliative end and of life care landscape and introduction

1. In 2020, over 62,000 people died in Scotland[1]; around 90% of those (almost 56,000) 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 locations, 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 chronic pain, as well as different types of pain
    - emotional, spiritual and psychological support
    - social care, including help with things like washing, dressing or eating
    - support for family and friends

3. But structural inequality fuels a vicious cycle of health inequality and inequity across Scotland, which has a profound impact on how and where terminally ill people can access palliative and end of life care. The intersection between long-standing issues creates a harmful combination affecting short and long-term health outcomes, which when someone is terminally ill and approaching the end of life, can be devastating.

4. Access to palliative and end of life support remains one of the most significant barriers for terminally ill people, their families and carers, and is experienced by many groups including older people, those living in rural communities, ethnically diverse groups, deprived communities, LGBTQ+ groups, people living with learning disabilities and women, among others.

5. Locality, a lack of knowledge about palliative and end of life care options, reluctance to engage with palliative and end of life care services and lack of care pathways among others, are long-standing issues which significantly impact end of life experiences of those affected by dying, death and bereavement in such groups.

6. These issues have been significantly exacerbated by the pandemic as a result of health and social care pressures, while emerging research has shown that Covid-19 has had a disproportionate impact on those living in socio-economic and deprived communities. But there are still many unanswered questions about exactly what palliative care support these groups were able to access, and how this impacted their end-of-life experience.

[1] National Records of Scotland: Vital Events References Tables 2019

7. The pandemic has shown the distressing impact dying, death and bereavement can have on anyone at any time, and the importance of easily accessible palliative care when it is needed most.

8. Scotland's ageing population means more people will be dying in the years to come. **Marie Curie research** projects 10,000 more people will be dying with palliative care needs by 2040, and people dying with co-morbidities (at least one condition) will have increased by 80%[2].

9. Many of these deaths will be in the community by 2040. Additional Marie Curie research projects that **nearly two-thirds of all Scottish deaths will take place in care homes, people's own homes or hospices**. Yet the pandemic has laid bare long-standing issues with health and social care integration, care coordination and workforce issues, highlighting the urgent need for reform of service infrastructures.

10. It is imperative that health inequalities for terminally ill people, their families and carers are tackled to ensure palliative and end of life support is accessible for those who need it most both now and in the future, otherwise terminally ill people will continue to be at risk of dying without support they need.

What progress, if any, has been made towards tackling health inequalities in Scotland? What has been successful and which areas require more focus?

What are the most effective approaches in tackling health inequalities and how effective is Scotland in pursuing such approaches?

What actions would you take to prioritise to transform structural inequalities that are the underlying cause of health inequalities?

The below response reflects all three of the above questions. There are many groups which are impacted by health inequalities, but Marie Curie has chosen to focus on age differentiation, poverty and deprivation.

11. In the 2016-2021 the vision of the Strategic Framework for Action on Palliative and End of Life Care stated that 'by 2021, everyone in Scotland who needs palliative care will have access to it'. Despite some progress, Scottish Government has fallen short of this ambition.

12. There has been some progress made towards Anticipatory Care Planning (ACP). 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.

13. 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.

[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)

14. 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[3].

15. However, there needs to be continual progress especially around recording carer information and ensuring people with all terminal diagnoses have a KIS in place, as the research also showed only 47% of those with organ failure had a KIS, compared to 80% of people with cancer[4].

16. 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)[5]. Public Health Scotland also identifies morbidity (disease) as an indicator of health inequalities[6].

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

18. 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[7].

19. 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.

20. 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. 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.

21. 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.

22. A specific focus needs to be given to providing more sustained funding for palliative care services in communities, and review of single disease health and social care models to reflect increasing multi-morbidities in patients.

23. The differentiation between age, when, and where people die in Scotland is also a clear determinant of health which must also be given urgent focus by this inquiry. Such differentiation is the consequence of structural inequality, where there are stark differences between the most and least deprived areas in relation to income, wealth and power.

---

[3] 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

[4] 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

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

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

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

24. This has a knock-on effect on outcomes including physical and mental health, housing and finance among others, which impacts access to palliative and end of life care, meaning terminally ill people could be at risk of dying without the support they need.

25. The impact of this is felt most acutely for those affected by dying, death and bereavement in the most deprived communities.

26. 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[8]. 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[9].

27. 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.

28. 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.

29. 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.

30. Age in the context of health inequalities should also considered in two phases, older people aged over 85 and those aged under 65.

31. Older people aged over 85 have the same care needs as those in younger age groups and have get the same access to palliative care. However, older people have more unmet pain, less access to palliative care services than younger people with clearer illnesses.

32. 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.

33. 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.

[8] Scottish Index of Multiple Deprivation 2020

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

34. 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.

35. 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.

36. Frailty is a complex, multidimensional problem associated with decline towards dependence and death[10]. 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[11].

37. 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.

38. It is vital that this inequality is addressed as part of the Scottish Government's new Palliative and End of Life Care Strategy, and is a priority for the new National Clinical Lead. As by 2040, the biggest increase in demand for palliative services is projected to be in those aged over 85.

39. Despite people under the age of 65 being more likely be identified and referred for palliative care support than those in older age groups, there is still significant inequality in place of care options for terminally ill people under 65.

40. For those under 65 living with a terminal illness, finding a suitable place of care can be challenging, and is often met with resistance from patient and family. This causes the process to be long and drawn-out causing distress as a patient approaches the end of life.

Case study, Marie Curie Hospice Glasgow

In 2019, a Marie Curie working group comprising of a service user/ volunteer, Inpatient Nurse Manager, Specialty Doctor, Lead Nurse and external stakeholder undertook a review of the Marie Curie Hospice Glasgow Inpatient Unit (IPU) with a focus on:

- IPU facilities, ensuring design supports the current and changing specialist palliative care needs of our population
- Effective utilisation of space
- Exploring opportunities for revenue generation

The review identified a gap in the lack of residential service provision for patients with longer term palliative and end of life care trajectories under the age of 65. It identified a local inequity of service provision for people with a terminal illness who require 24-hour nursing care, have complex physical and psychosocial needs with a longer-term prognosis of weeks to months, of end of life.

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

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

The catchment area of the Marie Curie Hospice Glasgow has a high level of deprivation. People who live in the most deprived quintiles are 1.2 times as likely to live alone than those in least deprived area, and have less access to informal carers. For these inpatients where home is not an option, long term care in in other care setting has to be explored.

Patients over 65 years, with a longer-term prognosis of end of life, have access to Health & Social Care Partnership (HSCP) funded Complex Palliative Care Beds with additional medical and nursing input. However, it was identified that there is currently no equivalent model for people under 65s living with a terminal illness.

A review of the Marie Curie Hospice Glasgow IPU between April 2019-April 2020, found 116 of 357 unique admissions were under the age of 65. However, for those under 65, the average length of stay was higher with a mean length of stay of 35 days and median of 30 days. Of those patients under 65 with a length of stay greater than 17 days, the following was identified.

- 58.4% of patients were in top 3 deciles of deprivation (37.7% in most deprived)
- 51/53 patients had diagnosis of malignancy
- Place of death: 79% - died within the Marie Curie Glasgow Hospice, at home (15%) and in hospital (4%)

Following the review of historical inpatient data, a cohort of in-patients with prognosis of weeks to months where return home was not possible were identified. In looking at reasons for this longer length of stay, out with the current hospice model of care, it identified that patients had more complex care needs or lack of family/ social support:

- Younger patients had a longer length of stay
- Themes of living alone, deprivation and burden of physical and psychological symptoms were all barriers to returning home
- Discussions and processes involved in care home transfer for younger people in last weeks or months of life can be a source of distress and often futile in the context of deteriorating conditions

The project found that the challenge associated with identifying suitable accommodation in care home provision, versus dedicated hospice beds for longer term care for those under 65 with a terminal illness, would enable continuity of care and avoid changes in care setting.

What has the impact of the pandemic had on both health inequalities themselves, and on action to address health inequalities in Scotland?

41. 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.

42. 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.

43. 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. Existing data has shown that deaths from Covid-19 were twice as high in deprived communities, leading to questions about the access to palliative support terminally ill people, their families and carers had access to because of health and social care pressures and Covid restrictions.

44. Where the number of deaths from Covid has been higher in more deprived communities, it is vital to recognise that the need for bereavement support will also be much greater.

45. Marie Curie believes that the Scottish Government Public Covid-19 inquiry should explore the disproportionate affect the pandemic has had on those groups. This should not be limited to those that experienced a Covid-19 diagnosis, but should look at the wider impact Covid-19 had on other areas of health and social care, including for those living with a terminal illness and approaching the end of life. We welcome the inclusion of end-of-life care in the terms of reference of the Covid-19 inquiry.

Can you tell us about any local, regional or national initiatives throughout the pandemic, or prior to it, that have helped to alleviate health inequalities or address the needs of hard to reach groups? How can we sustain and embed such examples of good practice for the future?

46. Before the pandemic, in 2018, Marie Curie and MND Scotland successfully led the campaign for the Social Security (Scotland) Bill to include a legal definition of terminal illness that was based on clinical judgement and not one that included timescales, as currently used by the DWP, to support decision-making for those applying for benefits through the Special Rules. This also means doctors and nurses can express this clinical judgement to determine someone as terminally ill to enable the quickest response possible.

47. The Child Disability Payment is now available nationally across Scotland, and Adult Disability Payment started being piloted in March and will be rolled out nationally in August 2022. This is extremely welcome, and will support thousands of terminally ill people in Scotland to live as well as possible until they die.

48. However, it will create a two-tier system in Scotland – as Universal Credit and Employment and Support Allowance will remain reserved to Westminster. These benefits will use the DWP's new definition of Terminal Illness under the Special Rules, which state that a terminally ill person must prove they have 12 months to live to be fast-tracked to receive their benefits.

49. This is deeply concerning, as it will require clinicians to use two different definitions of Terminal Illness, and potentially reach two different conclusions for a person who is terminally ill needing to access disability benefits, adding layers of complexity and potential delays for dying people in Scotland. It also highlights continued, structural inequality which must be addressed.

How can action to tackle health inequalities be prioritised during Covid-19 recovery?

What should the Scottish Government and/or other decision makers be focusing on in terms of tackling health inequalities? What should be treated as the most urgent priorities?

The below responses reflect the above two questions.

50. Covid-19 has shown the distressing impact dying, death and bereavement can have anyone at any time. The Scottish Government has committed to a new national Palliative and End of Life Care Strategy which is welcome, but must be used as an

opportunity to tackle long-standing health inequalities in palliative and end of life care, primarily equitable access to services.

51. The strategy must reflect experiences of the pandemic and reflect key learnings from existing evidence and as this evidence base broadens over time, to ensure that long-standing issues with health and social care integration, care coordination, workforce recruitment and retention and sustained funding in community services are addressed. As these contribute significantly to health inequalities for those affected by dying, death and bereavement.

52. Local communities had a pivotal role in supporting the most vulnerable, as many initiatives evolved overnight when the pandemic began in 2020. There is a clear appetite from communities to be part of initiatives which support the most vulnerable, including those affected by dying, death and bereavement.

53. But there needs to be recognition that the statutory response is not enough. We believe greater mobilisation and investment in community-care support services is needed for everyone through Compassionate Community models, such as Compassionate Inverclyde, which help provide information, support and day to day respite to cope with the pressures and implications of caring for a terminally ill person at home. This is especially important given a projected two-thirds of people will die in community-based settings by 2040.

54. This should include outreach to those most affected by health inequalities, including those in rural communities, deprived areas, ethnically diverse groups, LGBQ+ among others.

55. But more widely, urgent prioritisation must be given to addressing the structural inequalities at the heart of these issues significantly impacting terminally ill people, their families and carers.

What role should the statutory sector, third, independent and private sectors have in tackling health inequalities in the future?

56. Marie Curie is the largest third sector provider of palliative care services for adults in Scotland. The third sector as a whole plays a key role in integrated services, yet is not seen as an equal partner and often not included in early conversations with Integration Authorities regarding the strategic planning and commissioning of services despite having extensive knowledge and skills. This includes for groups most affected by health inequalities.

57. We believe the third sector must be included as voting members of all Integration Authorities in Scotland, and included in the strategic planning of palliative care services to ensure support is accessible to everyone affected by dying, death and bereavement for the best possible end of life experience which reflects what is most important to them.

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.

Further information:

Ellie Wagstaff
Marie Curie
Policy and Public Affairs Manager
Ellie.wagstaff@mariecurie.org.uk
@MarieCurieSCO
@wagstaff_ellie

Marie Curie
Care and support through terminal illness