Marie Curie Response

Scottish Parliament Health & Sport Committee
Social Care Inquiry

Introduction and overview of current palliative end and of life care landscape

1. In 2018, there were around 58,500 deaths registered in Scotland[1]. It is estimated that 48,875 of those who died had a palliative or end of life care need. But, one in four people still miss out on this support across the country. 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. 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.

3. Struggling health and social care systems which have become compromised on multiple levels mean social care delivery is currently reactive and costly with unsustainable, complex caseloads for already exhausted social care workforces. This is causing significant pressure on other services including in acute settings, such as the emergency services, which can mean people often die in hospital when they would rather be at home.

4. Demographics of people with a terminal illness are also changing, as people are living longer with more complex conditions. There will be nearly 16% more deaths in Scotland by 2040, with 45% of all deaths aged over 85[2], and many of those living with multiple health conditions, including frailty. This highlights the need for early intervention and greater advanced care planning.

5. As many as 10,500 more people will die from disease(s) associated with palliative care needs by 2040[3], and further recent research led by Marie Curie explores the most common places to die in 20 years' time , projecting that up to two thirds of people in Scotland could die at home, in a care home or a hospice.

6. In order to support this trend, our research notes that a significantly increased demand for community-based palliative and end of life social care will be needed. However, this won't be achieved without substantial financial investment and reform of the current

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[1] In 2018, 58,503 deaths were registered in Scotland https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthly-data-on-births-and-deaths/monthly-data-on-births-and-deaths-registered-in-scotland

[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) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x

[3] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x

system, moving to a more proactive system, based on advanced planning and co-ordinated care which is delivered in partnership with the patient and recognises the role of family carers. This will include investing in the social care workforce by valuing its role in supporting terminally ill people and supporting them to deliver that care, with the time they need to do it.

7. Everyone will be affected by dying, death and bereavement, and reform of care for those with palliative and end of life should be a high priority for Scottish Government to enable people to die well, with the support they need.

Question 1 – How should the public be involved in planning their own and their community's social care services?

8. Person-centredness should be at the heart of all community-based care provision, and Marie Curie welcomes further involvement of the public in planning their own community social care services.

9. We believe strategic planning for these services should be led by health and social care services with local stakeholder groups in conjunction with a programme of community-led consultation exercises, using a transparent approach to give people an honest understanding of exactly what resources are available to them. This will provide an opportunity for gaps to be identified and enable informed and realistic discussions about options for community social care provision, so that the care provided is consistent, sustainable and specific to the community's needs.

10. Using a variety of written and verbal engagement methods is vital for reaching as many people as possible in the consultations, and creates inclusive, equal environments which enable opinions to be publicly shared, or expressed anonymously. Marie Curie suggests engagement methods such as; verbal community sessions (e.g. open town hall sessions or take the consultation to places people receive care such as doctors' surgeries and health centres, suggestion boxes could also be left in these locations), hand-written submissions, online surveys/questionnaires and online discussion forums (including on social media). Such engagement must include people with palliative and end of life care needs, their families, carers and those delivering palliative care services.

Question 2 – How should integration authorities commission and procure social care to ensure it is person-centred?

11. Marie Curie believes palliative and end of life care must be an integrated part of health and social care to enable patients and families to get the support they need regardless of where they are and as they move through different care settings.

12. There are significant challenges with engagement between third sector and IJBs in relation to identifying contacts and establishing working relationships to enable strategic discussions[4]. We appreciate that much of third sector engagement with IJBs at Board level must be channelled through Third Sector Interfaces (TSI), but this has been minimal to date in some areas. In our experience, a large proportion of TSIs believe 'national' charities, such as Marie Curie, are either not present locally or able to represent themselves to IJBs and thus do not actively engage third sector in consultation work or

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[4] Marie Curie Integration Parliamentary Briefing https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-briefings/marie-curie-integration-briefing-october-2019-fv.pdf

activity around IJBs. We believe there needs to be clearer engagement and understanding at strategic and operational levels as without it, neither side maximises the opportunities the other has to offer to deliver person-centred care.

13. We recognise financial pressures on commissioners, and the effort by some to take a more open, person-centred approach to social care provision for those with palliative care needs and end of life, but there is still much more which can be done to innovate services which improves care and meets needs. Unfortunately, too many third sector organisations are relying on 12-month funding contracts to deliver palliative and end of life social care with limited evaluation which brings considerable uncertainty. We believe IJBs must involve the third sector as early as is feasible in identifying the needs of local populations and in developing and designing sustainable service responses to meet those needs over time. Recent reviews by the Scottish Government to ensure three-year rolling contracts for the third sector needs to be revisited, and also needs to be a common place for integration authorities.

14. Commissioning packages of care has become a postcode lottery by IJBs, which presents significant challenges and varies in different regions based on population and urban/rural locality. In some parts of Grampian, for example, there is little or no social care provision leaving terminally ill people and their families at breaking point, often forcing a preventable hospital admission.

15. Delayed care assessments for social care packages, which are often subsequently rigid and inflexible in how they have to be accepted, means patients can wait considerable lengths of time before being discharged from hospital. Some patients may be discharged from hospital with the support of alternative services, such as Marie Curie's Fast Track and Rapid Response services, which provide intense health and social care support for a short period of time until social care packages can be put in place. However, not every area can access these services, and where they are available there are capacity issues meaning that not everyone that needs to be supported can be. Our Fast Track service in Glasgow has already seen a 20% increase in the demand of the service this year and are predicting further growth.

16. Many that are discharged from hospital may also be quickly readmitted because care needs remain unmet in the community We are also aware of patients in communities who need urgent care and are at risk of being admitted to hospital, but are facing significant waits for help. This is the worst possible scenario especially for patients with a short prognosis of only a few weeks or months, causing significant amounts of stress and discomfort.

17. There needs to be greater investment and support for services such as Marie Curie's Fast Track and Rapid Response services, which have been proven to support thousands of patients and reduce hospital bed days and admissions[5].

18. Further Marie Curie research shows that if current trends continue, deaths caused by dementia are expected to rise to around 136,190 (projected increase of 185%) by 2040[6], in addition to high levels of cancer related deaths. These are projected to be the dominant illnesses accounting for palliative care needs in 20 years' time. Our research also notes

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[5] https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/partnership-case-studies/glasgow-and-lothian-getting-people-home-with-the-support-they-need.pdf

[6] Marie Curie 2040 Project (2019)

that the number of frail patients could significantly increase to 94% in over 80s, and there is estimated to be 307,000 more people aged 65 and over living with a multi-morbidity by 2040[7]. As large proportions of patients living with these conditions receive social care either at home or in community settings, future care models must be able to support these needs.

19. Having this knowledge of local care trends, patterns and needs also enables informed projections to be made for future palliative and end of life care models/frameworks which is an essential part of this process, as by 2040, community settings could account for two-thirds of all deaths, which are complex, according to Marie Curie research.

20. Marie Curie believes a proactive, assets-based approach to the commissioning and procurement of social care should be taken by Health and Social Care Partnerships. This would allow it to be more reflective of specific local community needs with the ability to adapt quickly when those needs change. We believe conducting an assessment of how existing assets in the community are utilised before scoping new opportunities would be both time and cost effective. A collaborative, systems approach between commissioners/integration authorities, service delivery partners and the community should therefore be considered to facilitate knowledge exchange, with all sectors seen as equals in the strategic planning and commissioning of social care services to meet specific community needs. First-hand feedback from communities around required local social care provision should also be incorporated into these discussions referenced in points 9 and 10 to maintain person-centredness.

21. By taking this collaborative approach, communication between all partners will improve leading to greater health and social care integration, and a transition away from silo working that is still evident in several areas, and results in disjointed services and poor care of terminally ill people. Marie Curie suggests commissioning bodies and integration authorities appoint a single point of contact to enable clear and rapid coordination between boards, social care service providers, carers, patients and families.

22. People living with a terminal illness can see their condition rapidly deteriorate. Social care packages and support service models must be flexible and reactive to ensure that people's needs are met rapidly following a decline in health. Services must also respond to the needs of carers as well.

23. A review of well-functioning existing care models and frameworks could be undertaken as part of this collaborative approach, adapting examples of good practice to specific regions while remaining flexible as needs of terminally ill people evolve.

24. A large proportion of social care models/frameworks are also rigidly confined to time and task, meaning carers are unable to provide the full extent of care patients may require (usually more complex for palliative or end of life care service users) because they only have 15-minute slots per patient. Lack of time can also significantly impact on advanced care planning conversations. Complex communications around a patient's health also means time and task models do not meet patients' needs, for example, emotional conversations about changes to a patient's condition, the need to move to a care home, or feelings of isolation or loneliness in a patient cannot take place in 15 minutes. We believe this time constrained approach to commissioning needs to be replaced with one which has person-centred outcomes at the heart of its delivery. Palliative and end of life

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[7] Marie Curie 2040 Project (2019)

care services, such as those delivered by Marie Curie, often do not follow these constrained models of care. Greater investment and support in such approaches and in organisations delivering these services, who could work in partnership with social care services, would improve patient outcomes and potentially relieve pressure on social care services.

Question 3 – Looking ahead, what are the essential elements in an ideal model of social care (e.g. workforce, technology, housing, etc.)? (This can also include business models/service redesign).

25. Taking a proactive approach to identify a person's current and future palliative and end of life social care needs as early as possible is essential to deliver person-centred care. Advanced care planning which can be adapted as needs change and can be delivered by workforces which feel valued and are appropriately skilled to provide care for terminally ill people must be a part of care packages delivered by social care teams. This would include wrap around support for the patient and would include any informal or family carer.

26. Advanced care planning (ACP) and information sharing are crucial facilitators for this and should be driven by collaborative discussions between health and social care professionals, patients and families to ensure both imminent and future care needs are met. Currently, engagement with ACPs is often too late at a point when patients are already in a rapidly deteriorating condition with families at breaking point. The development of an ACP for a patient and carer should be the starting point with a fully integrated health and social care response put in place to meet those needs.

27. Recent Marie Curie led research shows there has been progress in the use of patient Key Information Summaries (KIS), with 69% of Scots having a KIS in place at the time of death, created on average 10 months before death[8]. However, there needs to be continual progress especially around recording carer information and ensuring people with all terminal diagnoses have a KIS in place. Our research showed only 47% of those with organ failure had a KIS, compared to 80% of people with cancer. We believe that social care staff should be empowered with the ability to access and update a patient's KIS in order to deliver informed, needs-based care and maintain strong health and social care integration.

28. We recognise the role the National Digital Platform is already playing but believe there is an urgent technological reform needed to facilitate effective information sharing (KIS and ACPs) which allows seamless communication between all health and social care providers.

29. With access to the National Digital Platform scheduled to open to citizens, we believe investment and training must be allocated to social care to equip workforces with the skills to support patients to be able to view their own records and use them in a way which helps them get the care they want and need.

30. Significant reform in recruitment and training of social care staff is an urgent priority to be able to retain workforces who feel valued, supported, and equipped with the right skills to deliver care on a daily basis. Much of the social care workforce does not currently have

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[8] 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

any palliative or end of life care training, yet they are expected to deliver it for patients at home and in care homes. Marie Curie proposes embedded palliative and end of life care education in social care training programmes to enable staff to feel confident and empowered to deliver the care terminally ill people need.

31. This could help reduce unprecedently high workforce turnover levels, which is currently creating a lack of consistency of carers meaning patients could be looked after by up to 15-20 different people per week. This is overwhelming and stressful for many, especially frail patients.

32. Emergency out of hours respite social care is also very difficult to access at present, and has a complicated, timely application process through social work and also places significant pressure on these resources as well. As a result, there are significantly high levels of hospital admissions or requests for inpatient hospice beds late at night because families have reached breaking point. Marie Curie's Rapid Response service provides care at short-notice to terminally ill patients and relieves families, but this is not enough to cover every patient who may need support and is not available in every area. We believe increased investment should be made to support rapid social care response services for palliative and end of life patients with a fast track element to mobilise care delivery quickly.

33. 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. We believe informal carer roles are equally as important as social care workforces in providing community palliative and end of life care, which Marie Curie recently discussed in a response to the Scottish Government's Carers Strategic Policy Statement consultation.

34. As our research has shown, many people prefer to die at home where possible. We believe implementing a fast track response should be explored which enables rapid implementation of housing adaptions for those patients who need it. For example, a patient with severely restricted mobility caused by a terminal illness, such as Motor Neurone Disease (MND), will need adaptions to their home to easily access facilities such as toilets and showers as their condition deteriorates. Home adaptions are a key part of community-based social care support to enable people stay at home for as long as possible, and a fast track service would allow urgent cases to receive support quickly. We propose that existing sheltered housing stock should be adapted to suit the needs people living with complex, terminal conditions and new housing stock produced should also reflect this approach to appropriately equip older generations. This will also support social care workforces in care delivery, especially for terminally ill patients with more complex needs.

35. Telecare technology also supports patients at home through fitting alarms, red button pendants and sensors usually for people at risk of falling or living with conditions where mobility is limited. The technology reacts to potentially harmful incidents detected from a person's movements, and helps raise a response quickly. Installing a key safe is necessary to allow carers and family members to access the patient quickly. Telecare gives people a sense of empowerment and independence in their homes, however, the

key safes are not currently provided by Local Authorities, meaning people must fund these themselves. Being assessed for financial support is an option, but is granted on a case by case basis. We believe key safes should be available universally free of charge as part of the Scottish Government's commitment to community-based care.

36. Self-directed support (SDS) is also an integral part of a person's care to help inform their choices about the care they want and need. Marie Curie welcomes the Scottish Government's commitment to £7.2m funding for Support in the Right Direction projects, but believes there are still severe issues which must be addressed in patient access to SDS highlighted by the fact only 1% of care home residents from care homes surveyed by Scottish Care were given the choice of available SDS options[9].

Question 4 – What needs to happen to ensure the equitable provision of social care?

37. Social care provision should be equally accessible across Scotland, yet there are still challenges with this access in more rural locations. Workforces have longer travel times to these areas which they are often not paid for and penalised if they miss their time slot altogether, causing stress for both workforces and patients. Restrictive time and task care slots mean they sometimes leave without being able to provide the full extent of care which terminally ill people need. These models are not person-centred, and should be replaced with a needs-based approach where care is tailored to each patient with more flexible slot timings. If social care staff were given access to a patient's KIS for example, it would allow appropriate care planning ahead of time.

38. Access to social care for deprived areas and minority groups such as BAME and LGBTQI+ also presents significant challenges, and is often overlooked. We believe there should be greater responsibility and accountability for Local Authorities to tackle the significant challenges between homelessness and deprivation and palliative care. As such, Marie Curie will be hosting two events in June 2020; a conference examining deprivation, dying and death - managing health inequalities at the end of life, followed by a summit on issue of homelessness and palliative care to inform the next phase of our work. Marie Curie believes community-based social care must be better supported to reach these groups, and suggests an initial mapping exercise could be undertaken to identify prominent issues in local communities e.g. older people with mental health issues, substance or addiction etc. to understand why terminally ill people in these settings do not engage with palliative and end of life care services. A reformed, more inclusive and person-centred approach to social care could be piloted in agreed locations for these groups, with feedback being incorporated into the new strategy to be implemented across the country.

About Marie Curie

39. 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.

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[9] Scottish Care, Rights at Home Report 2020 https://scottishcare.org/news-release-rights-at-home-sds/

40. Last year we provided care for over 7,500 people living with a terminal illness, as well as their families and carers across Scotland.

41. 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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