

HEALTH AND SPORT COMMITTEE

SOCIAL CARE INQUIRY

SUBMISSION FROM MARIE CURIE

Covid-19 follow-up to Health and Sport Committee Social Care Inquiry

Overview

Social care is an essential part of the care and support that terminally ill people receive, helping them to live as well as possible right up until their death.

Long-standing, fundamental issues in social care in Scotland including lack of sustained financial support, workforce challenges and compromised systems **have been exacerbated by the coronavirus pandemic**. When combined with more specific **Covid-19** related issues such as lack of Personal Protective Equipment (PPE) and a sudden shift towards community deaths, the pandemic **has significantly impacted the care terminally ill people receive** and placed already exhausted workforces under further, intense pressure.

Marie Curie believes this crisis has emphasised the need for urgent review and reform of current Scottish social care system to become more integrated and proactive, and we welcome the inclusion of the impact of Covid-19 in the Health and Sport Committee's current Social Care Inquiry.

Introduction and Headline Statistics Pre-Covid

Everyone is affected by dying, death and bereavement at some stage of their lives, and is entitled to an end of life experience which reflects what is most important to them. But this cannot happen without social care services, who deliver the high quality, person-centred care terminally ill people need in communities, including their own homes and care homes, at the end of their lives.

In 2019, there were around 58,100 deaths registered in Scotland¹. It is estimated that 44,000 (75%) of those who died had a palliative or end of life care need. **Marie Curie supported around 8,500 people last year** through our two hospices, nursing care and support services across Scotland.

- **Social care can help those who are terminally ill to remain at home** for as long as possible, if that is their wish, through providing tailored, day-to-day support. Social care teams often work in partnership with specialist palliative care providers, such as Marie Curie to deliver that care.
- Seven out of ten people cared for by Marie Curie nurses die in their own homes. On average, **over 94% of patients supported by Marie Curie in 2019/20 died in their place of choice** (often at home).

¹ In 2019, 58,108 deaths were registered in Scotland [National Records of Scotland: Vital Events References Tables 2019](#)

However, one in four people still miss out on palliative and end of life care across the country², which has been potentially worsened by Coronavirus.

Examining the effects of Covid-19 on the social care sector

Health and social care staff have been on the frontline in the fight against Coronavirus providing palliative and end of life care in all settings (hospital, care home, home, hospice) for thousands dying patients every day, some of whom were terminally ill and Covid-19 positive.

Marie Curie and other health and social care workforces provided vital support to the NHS by keeping these patients nearing the end of their lives out of hospital and reducing pressure on acute and critical care capacity. Evidence from the pandemic highlights **a reduction of over 1,000 (non-Covid related) deaths in Scottish Hospitals**³, leading to a substantial increase in the number of deaths in people's own homes and care homes.

At Marie Curie, we adapted and innovated the way our hospice and nursing services were delivered to ensure person-centered care for terminally ill people at the end of their lives could still be cared for.

However, an initial lack of Personal Protective Equipment (PPE) and a shift from hospital to community deaths has had a direct effect on the care sector.

PPE; Impact on Patient Care and Workforces

At the beginning of the pandemic, Marie Curie's frontline services faced a critical shortage of PPE in the first few weeks despite following the correct access processes, numerous requests for support and efforts to identify alternative sources. These issues had a direct impact on patient care – with some Marie Curie nursing visits to patients having to be cancelled because we did not have the PPE to deliver care safely.

It appears there was a significant lack of organisation in the early stages of the pandemic and, consequently, confusion in both central and local Government about who should be supplying PPE to non-NHS frontline services.

For the PPE we did receive through these channels, **Marie Curie had to rely heavily on its internal structures to support direct provision to our frontline staff across the country**, which involved some staff making **400 mile roundtrips** to ensure our nursing teams had the PPE they needed for visits to terminally ill patients - an unnecessary diversion of resources which were already under intense pressure.

We made efforts to buy the equipment we needed from alternative sources, but this had mixed results. Some suppliers were profiteering – charging substantially more for items such as face masks – but faced with such an enormous shortage we had little choice but to buy at inflated prices.

² <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

³ National Records of Scotland: <https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-report-week-28.pdf>

While most of these issues have now been resolved and local process hubs are more established, the initial lack of PPE meant some dying patients missed out on some of the essential care they needed.

Increase in Community Deaths

Data from National Records Scotland (NRS), has shown a significant shift in place of death from hospitals to communities during the pandemic for the vast majority of non-Covid patients over the last four months⁴. There has been an increase in cancer deaths at home with 907 more deaths than average during this period, dementia deaths have seen an increase in both care home and home settings, and there have been nearly 600 extra respiratory deaths at home. There has been a significant reduction in hospital deaths for people dying of non-Covid conditions at the same time. In normal times, dying at home is where the majority of patients tell us they want to be, thus we believe elements of this shift could be positive.

There have clearly been innovations and service responses to meet this shift (see case study below), however, there are some serious questions that need to be answered regarding the care that this group of people, particularly those dying at home have received during this time:

- What care did they get and who provided that care?
- What support from family carers did they get and what support did those carers get?
- What bereavement support was available?
- Will this trend continue or will there be a return to the increased hospital deaths?

Marie Curie has **serious concerns that many of these people will not have received the care they needed**. This will include accessing health and social care services, as well as community support. In some cases, this may have meant patients dying without proper pain or symptom management, with **family carers overwhelmed by the demands of caring, and struggling with grief and bereavement following the death of the cared for person**.

There has also been a lack of out-of-hours support for many patients (24-hour service not available) but there has been anecdotal evidence to suggest that the extra support through family members working from home or being on Furlough has helped with care.

It is vital that **health and social care staff are practically and emotionally supported** by Health and Social Care Partnerships to manage this shift in care, but equally **informal and family carers need to be supported as well**.

We are urging for research and evidence to be captured to understand the experience of these people and their carers to ensure that good practice is identified, lessons are learned, and additional support and resources are put in place to ensure that people

⁴ *Ibid*

get the care they need if this shift in care into the community is to be maintained for terminally ill people.

Case Study

Throughout the pandemic, our Marie Curie nursing services in Glasgow have been particularly affected by increased of deaths in the community due to Covid-19 prevalence in this region.

Trends emerged of high numbers of late patient referrals from District Nurses caused by families not engaging with services until breaking point due to fears of Covid-19 infection, or increased family support from either working at home full time or people on furlough. This meant a large proportion of the terminally ill patients we cared for at home through our Fast Track, Rapid Response and Managed Care services were at the end of their lives with a prognosis of just 2-3 days.

Our Glasgow Fast Track service team also experienced eight deaths in one weekend.

Advanced Care Planning

There is strong evidence to show that early advanced care planning (ACPs) leads to better outcomes for patients with terminal conditions, evidence suggests that (pre-covid) **less than half (47%) of patients have a Key Information Summary (KIS) at death**⁵.

Due to the rapidly evolving and unpredictable nature of Coronavirus and demands in clinical/acute settings, **clinicians did not always manage to discuss ACPs (and DNACPRs)** with patients in care homes or at home.

As a result, **this responsibility repeatedly fell to social care staff** who were not always appropriately trained to have difficult conversations, quickly, with patients and their families about their care. This **caused severe distress** among many social care workers and when combined with unusually high numbers of patient deaths in community settings, we have heard of some staff experiencing trauma or PTSD.

Despite caring for dying patients every day, high patient caseload numbers either at home or in care homes over short periods of time will inevitably impact on the mental health and wellbeing of social care staff.

This highlights that the shift from hospital to community deaths must be appropriately managed by Health and Social Care Partnerships to ensure social care workers are fully supported both practically and emotionally to deliver the palliative and end of life care that terminally ill patients need.

Examining wider issues impacting social care delivery that have come to light because of Covid-19

Family (Informal) Carers

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6917358/>

The role of family carers in a person's palliative and end of life care is crucial in helping terminally ill people get the day-to-day support they need for a good quality of life. But support for family carers themselves is often overlooked and needs to be more greatly recognised⁶.

Family carer breakdown is the most likely factor in a person with a terminal illness being admitted to a hospital, hospice or a care home⁷. Having a live-in carer is also the single most important factor in whether someone is able to die at home or not⁸. This highlights the need for support for carers and the importance of identifying them and putting in place a plan to assist them to continue their caring role.

Anecdotal evidence from our services is that many people with family carers have throughout the pandemic been slow to engage with services and often much later at crisis point. This has caused further challenges, as highlighted above.

It has been estimated that **an additional 400,000 people took on unpaid caring roles during lockdown** due to health and social care restrictions, **taking the total number of unpaid carers in Scotland to almost one million**⁹. Before Covid-19, Scottish unpaid care worth was reported at £36bn.

Support for family carers must be increased. Carers need to be identified by health and social care professionals and then referred for support where appropriate, including for an Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS). For those caring for someone with a terminal illness it will be important that this support is prioritised and fast tracked to avoid a breakdown in care¹⁰.

Carers should be able to access respite care when needed, as well as information and peer support through carers centres, and others, to enable them to continue to provide care to the person they are looking after and maintain their own wellbeing. This is especially important given the recent shift from hospital to community deaths as a result of Covid-19, as well as the projected increase to two-thirds of people dying in community-based settings by 2040.

Staff Wellbeing

Wellbeing of social care staff has been a long-standing issue in workforces, contributing to poor recruitment and retention. The Coronavirus pandemic has exacerbated this further through an initial lack of adequate PPE which contributed to stress and anxiety among social care workforces providing care to terminally ill patients in communities.

⁶ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curie-and-macmillan-getting-it-right-for-carers-final-report-november-2018.pdf>

⁷ <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ABC%20Palliative%20Care.pdf>

⁸ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

⁹ https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

¹⁰ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curie-and-macmillan-getting-it-right-for-carers-final-report-november-2018.pdf>

Combined with high caseloads, a significant shift from hospital to community deaths and difficult conversations about ACPs (DNACPRs), many social care staff have experienced trauma which may have a lasting impact on their mental health.

This has re-enforced the need for more palliative and end of life care training for social care staff to be available and undertaken to ensure they are equipped practically and supported emotionally. Marie Curie called for this in our initial response to the Health and Sport Committee's Social Care inquiry.

Marie Curie's existing employee assistance programme to support the wellbeing of our staff was supplemented with additional mental health training for our Clinical Nurse Managers to support staff returning to work. These have been well received by our teams, with noticeable changes in our staff.

Our staff also formed their own Covid-19 network to share knowledge, experiences and learnings between teams which further supported our Clinicians, Nurses and Healthcare Assistants going into patients' homes to deliver the palliative and end of life care when they needed it most.

Exploring how those lessons can be applied in the future to improve social care systems and delivery in Scotland.

Marie Curie research has shown that demographics of people with a terminal illness are changing, as people are living longer with more complex conditions.

What does this mean for future?

- As many as 10,500 more people than at present will die from disease(s) associated with palliative care needs by 2040¹¹
- There will be nearly 16% more deaths in Scotland by 2040
 - 45% of all deaths will be people aged over 85¹²
 - Many of those will be living with multiple health conditions
- Up to two thirds of people could die at home, in a care home or hospice by 2040

These projected trends show there will be a significantly increased demand for community-based palliative and end of life care in the next two decades.

Health and social care systems have historically struggled financially, including with capacity and workforces. This has been supported by The Scottish Advisory Group on Economic Recovery which published a report and recommendations for the coming months, including the future of the care sector.

¹¹ 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>

¹² 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>

The report recommended that the Scottish Government should accelerate work on social care reforms and urgently review structure, funding and regulation of the care sector to ensure sustainability and quality going forward. It also referenced workforce issues, and the need to recognise and support the contribution of unpaid carers.¹³

What needs to change for future social care delivery systems?

Integrated workforce plan. We need to ensure that Scotland has a workforce plan that ensures sufficient health and social care staff are available to provide appropriate care and support to people living with a terminal illness and approaching the end of life. This must include every aspect of palliative care, including emotional and spiritual support, as well as physical and symptom support. Without social care support, terminally ill people will be unable to get the end of life care they need to live as well as possible and, to die with dignity.

- **Urgent reform of social care models.** Without this Scottish social care services will be unable to cope with both immediate and projected social care demand. This will place even more pressure on emergency services, and push families caring for someone with a terminal illness to breaking point through not being able to access the right support or respite.
- **Greater investment in community-based care.** This includes supporting more care homes and care at home services to care for terminally ill people at the very end of life supporting the shift from hospital to community. This will include training and education for staff.
- **Investment in Compassionate Community models.** There is currently not enough statutory support available in the community to care for people who are terminally ill and approaching the end of life¹⁴. There needs to be investment in primary care, social care and community based palliative care services, including those delivered by the third sector. However, we also need to see greater investment in our community assets and support more community responses for those with a terminal illness, such as the Compassionate Inverclyde project. We would encourage the Scottish Government and Health and Social Care Partnerships to explore support for Compassionate Community approaches across Scotland.
- **Upskill the community health and social care workforce.** The Coronavirus pandemic has renewed calls for training in palliative and end of life care for social care staff to ensure workforces are well equipped practically and fully supported emotionally.
- We believe informal carer roles are equally as important as health and 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.

¹³ [Towards a robust, resilient wellbeing economy for Scotland: report of the Advisory Group on Economic Recovery](#) p.51

¹⁴ <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x>