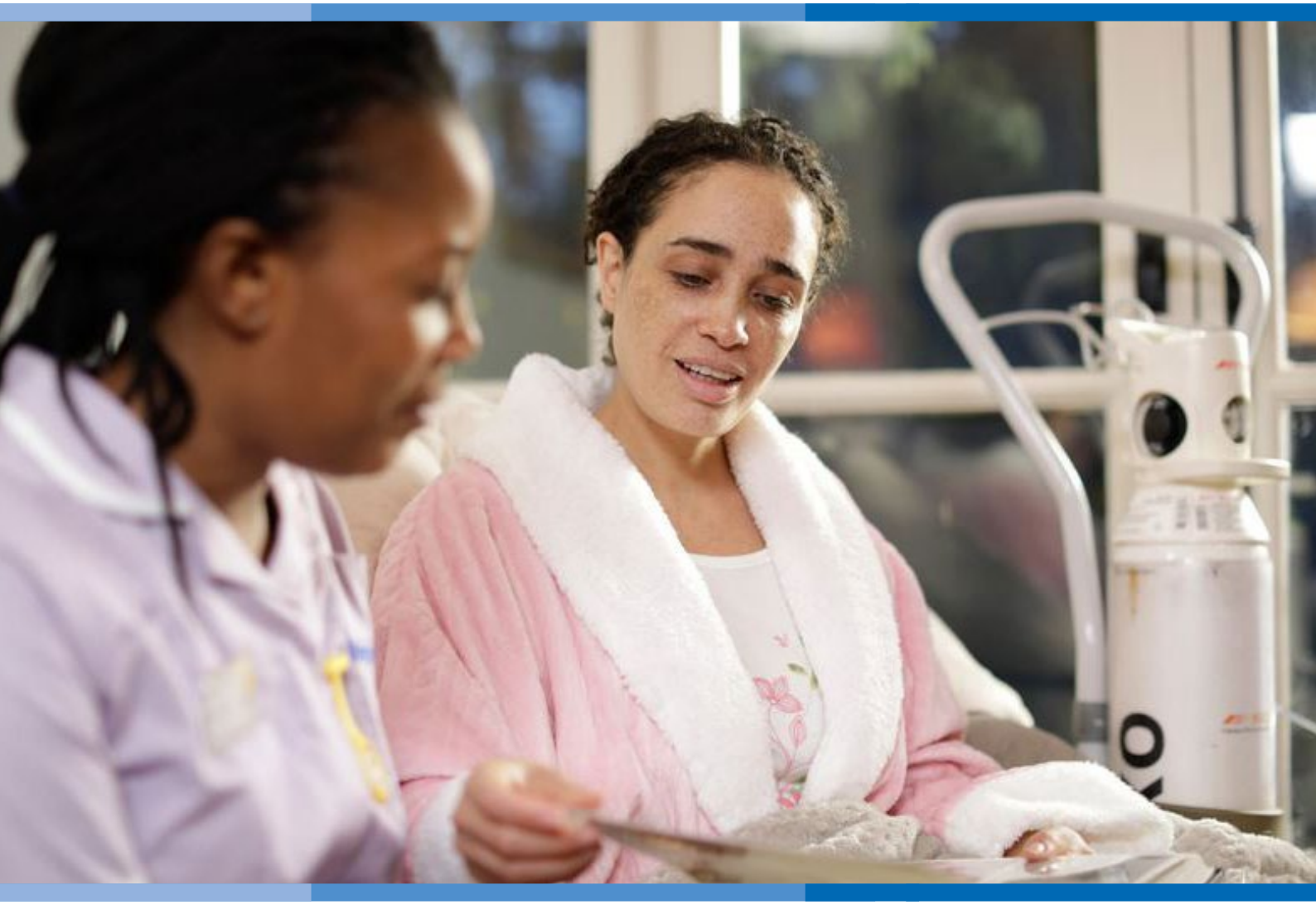
Marie Curie

Care and support through terminal illness

2021 Scottish Parliament Manifesto

Dying, death and bereavement: Getting it right for all of Scotland



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Introduction

In Scotland in 2019/20, more than 58,100 people died[1]. Around 90% of those (52,000) had a palliative care need in the final years, months, weeks, days and hours of their life. Scotland's ageing population means more and more people will be dying in the years to come, with Marie Curie research suggesting up to 10,000 more people dying every year with palliative care needs by 2040[2]. More and more of those people will be dying in the community, with nearly two-thirds of all deaths taking place in care homes or people's own homes[3].

Many of those living with a terminal illness will be supported by families, loved ones and neighbours, who provide them with informal family care. There is a growing need to support these carers throughout their caring role and beyond, especially when the person being cared for has died. Every year, it can be estimated that around 40,000-50,000 carers in Scotland are bereaved[4].

The coronavirus pandemic has shown the distressing impact dying, death and bereavement can have on anyone at any time. It has intensified the complexities associated with terminal illness for patients, families and carers, which will affect many people for years to come. The need to identify people with a terminal illness who would benefit from palliative support as early as possible has never been greater. This will ensure the best possible quality of life.

Everyone will be affected by dying, death and bereavement at some stage of their lives. Those who are dying have the right to an end of life experience which reflects what's most important to them.

Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care, guidance and support to help them make the most of the time they have left.

In Scotland in 2019/20

We cared for 8,534 people with a terminal illness

We need to raise £250,000 a week to support our services in Scotland

Our fundraising, care and support services:

- **2** hospices
- **2** research leads posts
- **15** active research projects
- **31** local authorities supported by our nursing service
- **32** stores
- **100** fundraising groups
- **175** people supported by our volunteer Helper services
- **1,571** volunteers
- **1/3** of care and support is provided by gifts in Wills.

Our vision 2021-2025

We believe the next Scottish Government must work towards a Scotland where dying, death and bereavement is talked about openly, where people can plan and discuss their care and preferences, and everyone affected has the best possible end of life experience which reflects what is most important to them.

Asks for the next Scottish Government

Marie Curie is calling for the next Scottish Government to support dying, death and bereavement in Scotland through three key asks:

1. Appoint a new National Clinical Lead for Palliative and End of Life Care for Scotland, who will be responsible for overseeing a new national strategy that delivers place-based palliative care in partnership with national and local stakeholders across public, private and third sectors.

2. Introduce a national strategy for palliative and end of life care taking a whole-system, public health approach that:

a. Sets out vision for care in all settings including hospitals, hospices, care homes and people's own homes.

b. Establishes a new national Palliative and End of Life Care Network linking key stakeholders with NHS Boards and Integration Authorities to identify gaps in care, share good practice and support innovation and learning.

c. Works with all providers including the NHS, social care, the independent and third sectors to ensure everyone gets the care they need and is working to end inequities and inequality.

d. Empowers and equips communities to care for and support those facing dying, death and bereavement to experience as high a quality of life as possible.

3. Ensure all family and other carers get the support they need as they look after the person they are caring for, and appropriate bereavement and financial support when that person dies.

Dying, death and bereavement impacts everyone and every part of our life. All public policy including health and social care, welfare, housing, education and technology will interact with people living with a terminal illness or when someone is grieving.

A whole-system approach to terminal illness should be adopted both nationally and locally from Scottish Parliament and Government to NHS Boards, and Health and Social Care Partnerships, Local Government and Community Councils.

Kieran Dodds/Marie Curie

What is palliative care?

We believe someone is terminally ill if they are diagnosed with a condition that will lead to their death. Depending on the condition this could be years, months, weeks or days.

Those who are terminally ill can be supported with a palliative care approach. The aim of palliative care is 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.

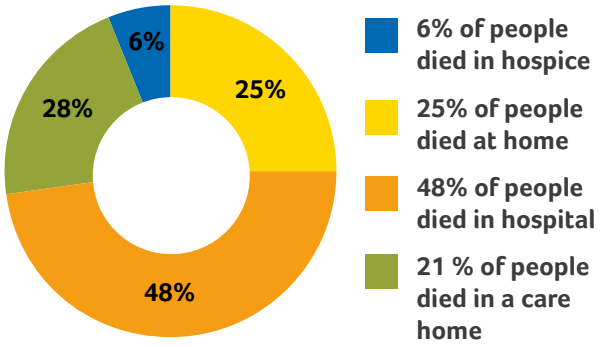
A person can receive palliative care at any stage of their illness. It can be delivered alongside treatments, therapies and medicines aimed at controlling the illness, such as chemotherapy or radiotherapy.

Palliative care can be provided in different places, including in a person's home, in hospital, in a care home or nursing home, and in a hospice. It can be delivered by general health and social care professionals, such as GPs, District Nurses and social care teams, as part of the day-to-day care they provide. A person may also receive support from specialist palliative care professionals who might be involved in managing more complex care needs. They will often work in partnership with other professionals to provide co-ordinated and personalised care[5].

Dying in Scotland today

In 2018, more than 16,500 people died of cancer, more than 14,700 died of circulatory disease, more than 7,000 died of respiratory disease and more than 4,000 died of dementia or Alzheimer's[6].

Figures below show where people died:



There are still misconceptions about palliative care, with it often being associated with people dying of cancer, but it supports a person with any terminal condition including dementia, frailty, heart disease. Many people will die with multiple health conditions[ii].

Currently, not everyone gets the support they need – one third of Scots with terminal conditions die without an anticipatory care plan in place, meaning they could be dying without some or any of the support they need[7]. Research carried out by the London School of Economics in 2015 also suggested a significant number of people who need specialist palliative care were not accessing it .

We know that many groups of people face difficulties accessing the care they need. The disease a person is dying from can increase or decrease the chance a person has of accessing palliative care services. Those with cancer are far more likely to get the care they need compared to those with other conditions, particularly those with organ failure[8].

The inverse care law applies in palliative care as it does in almost every other aspect of life[9]. Minority, deprived and rural communities are all far less likely to get the help they need as they approach the end of their lives[10]. 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[11].

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[12]. More research is needed to better understand this.

Dying in Scotland in 2040

Marie Curie research suggests that between 2017 and 2040, Scotland will see a 14% increase in deaths, rising from 57,870 to a predicted 65,756 in 2040. **Research suggests that up to 95% of those deaths are likely to require a palliative care approach – this means nearly 10,000 more people dying who will need a palliative approach in Scotland every year[13].**

Trends in place of death show that by 2040, up to two-thirds of people in Scotland are likely to die in a community setting, including their own homes, care homes and hospices, with hospital deaths accounting for 34% (down from 50% in 2017)[14]. The same research also suggests that without investment in social care services this will not be possible.

Data from the National Records for Scotland has already started to show a shift in care to the community is increasing, with more and more people dying at home or at their care home. There has also been a steady increase in recent years in the amount of time people spend in the community in their last six months of life[15].

During the recent COVID-19 pandemic there has also been a significant and substantial increase in the number of people dying at home. There were 4,000 more deaths at home in 2020 than in previous years, with 1,500 more people dying at home with cancer, nearly 1,000 more heart disease and circulatory-related deaths, and increases in dementia and respiratory-related deaths at home. This has largely been driven by the need to free up hospital beds for patients with coronavirus. If this trend continues, then it is important to make sure these people are properly supported with all the care and support they and their carers need as they approach the end of life.

The next Scottish Government will see these changes accelerate toward the 2040 projections.

We need to see action now, to ensure that we can meet this challenge and ensure that people who are dying and approaching the end of their lives have the best possible experience, and for that experience to reflect what is most important to them.

It is the duty of the next Scottish Government to meet this challenge and ensure that we get it right for every person at end of life.

Being identified for and accessing palliative care

One of the biggest challenges facing people who are diagnosed with a terminal illness is being able to access the care and support they need. A lot of people who miss out on some or all of the care they need is because they are not identified for a palliative approach and never have a chance to discuss with health and social care practitioners or their family the kind of support they need, their wishes and how they would like to spend the time they have left.

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.

An Anticipatory Care Plan (ACP) can allow patients and healthcare teams to discuss treatments and care options, as well as preferences such as place of care and where a person would prefer to die. It also allows a social and spiritual preferences and wishes to be captured and acted on, as well as help identify any carers.

69%

Currently, only 69% of people with a terminal illness have an electronic care plan in place in Scotland

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.

Currently, only 69% of people with a terminal illness have an electronic care plan in place in Scotland[16]; with those with terminal cancer more likely to have one than those with other conditions. This rate has been improving, but we need to see everyone with a terminal illness be given the opportunity to develop an ACP.

The Scottish Government committed to everyone who needs palliative care having access to it by 2021, including a commitment to ensuring that everyone who needs an Anticipatory Care Plan will have one. Evidence currently suggests that Scotland is short of meeting this ambition and more must be done to ensure that people who would benefit from an ACP have the opportunity to get one.

- **Every person diagnosed with a terminal illness should be given the opportunity to have and discuss an Anticipatory Care Plan, which can be read, updated and easily shared electronically by anyone responsible for that person's care.**
- **The urgent roll-out of the National Digital Platform to facilitate accessible, easy exchange of ACPs between all care providers, with appropriate digital training for health and social care workforces. Patients and carers, where appropriate, should also be able to access ACPs.**

"Until I had personally had to be involved in meetings to discuss care for my gran, I had no idea that there were so many requirements, so many forms or that the waiting times for assessments could be so long. I think that if people had a better understanding of what might happen then they would take steps to prepare and make sure their loved ones won't be faced with worry over what is the right thing to do."
Marie Curie staff member

Health inequities and inequalities in palliative care

More must also be done to tackle inequalities and inequities in access to palliative and end of life care. There are many groups and populations that struggle to access vital health and social care services, including palliative care. These include rural communities, ethnic and socially deprived groups, gypsy and traveller communities, LGBTQ+, women, older people and people with learning disabilities.

A lack of knowledge about palliative and end of life care options, and a reluctance to engage with palliative and end of life care services are long-standing issues which significantly impact palliative and end of life experiences for these groups.

Local statutory services for minority groups are often under-resourced and work in silos, meaning a large proportion of people in these groups fall between the cracks and are let down by unnecessarily complex systems. Existing research has shown that fear of discrimination, a lack of knowledge about palliative and end of life care, and not knowing where to find support can also cause poor engagement with specialist care providers.

Gender inequalities

- International research exploring gender and palliative care has shown that women face significantly more barriers in accessing the palliative and end of life support they need, primarily as a result of different social circumstances and existing gender stereotypes around care giving, among others[17]. There is significant evidence gap for this group in Scotland, which must be explored.

Ethnically diverse groups

- Marie Curie research has shown that many from ethnically diverse groups including Black, Asian and other minority groups are not accessing palliative care and, when they do, palliative care delivery is not always sensitive to their different needs, particularly around culture and religion[18].

LGBTQ+

- One in six LGBTQ+ people are discriminated against using public services including palliative care, and half of LGBTQ+ people expect to be discriminated against. This can mean LGBTQ+ people delay accessing the health and social care services they need, making the process seem overwhelming, particularly at the end of life when they are most vulnerable[19].

Older people

- Older people are much less likely to get the palliative care they need at end of life compared to younger age groups, primarily because their condition and prognosis can be seen as a normal part of dying. They often have unmet pain needs as a result of this and struggle to access palliative care specialists who can co-ordinate services for them, such as Clinical Nurse Specialists[20].
- **We are calling for the Scottish Government's Ministerial Task Force on Health Inequalities to include a specific focus on palliative and end of life care to ensure everyone has equal access to the palliative support they need.**

Talking about dying, death and bereavement

Dying and death remains a taboo subject in the general population. Palliative care still carries with it an association with crisis intervention and/or imminent death, which means the benefits of early engagement are often not fully understood or taken advantage of, or missed altogether.

Many organisations and movements, such as the Good Life, Good Death, Good Grief alliance, have tried to encourage a more open society willing to talk about these subjects, but more needs to be done.

Marie Curie supports Good Life, Good Death, Good Grief's End of life Aid Skills for Everyone (EASE) resource, which has been designed to enable people to be more comfortable and confident in issues they face around dying, death and bereavement.

We believe that initiatives like this need greater support and investment and that the Scottish Government should take more of a role in leading this national debate.

- **The Scottish Government should lead a national public health discussion around dying, death and bereavement.**
- **The Scottish Government must better support existing resources and invest in new ones to help everyone affected by terminal illness feel equipped to manage issues relating to dying, death and bereavement in addition to well-signposted and accessible physical, emotional and spiritual support.**

Community support networks

Local community networks, including faith groups, can provide a vital source of support for terminally ill people, their families and carers.

Compassionate Community initiatives, such as **Compassionate Inverclyde**, which was established by Ardgowan Hospice in 2016, help provide information, support and day-to-day respite for informal carers to cope with the pressures and implications of caring for a terminally ill person at home, as well as a release for patients themselves. This is especially important, given a projected two-thirds of people will die in community-based settings by 2040.

The Truacanta Project which is run by the Scottish Partnership for Palliative Care (SPPC) was set up to support local communities across Scotland interested in taking community action to improve people's experiences of dying, death, loss and care. A number of projects have been identified and will be supported in the coming years.

There is undoubtedly potential to harness the resource, compassion and dedication of communities more deliberately and efficiently than is currently the case. The pandemic has shown how quickly community initiatives can be mobilised and the difference this can make for the most vulnerable.

- **We are calling for the establishment of a Compassionate Communities Network across all Integration Authorities, with identified resource to support capacity building in communities.**
- **Empower and train volunteers to help bridge statutory and non-statutory support and act as an early-warning system to health and social care teams as needs of those affected by terminal illness change.**

Integration of health and social care

The health and social care system is still less integrated than was intended when the Public Bodies Act was passed. 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.

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.

- **The third sector must be included as voting members of all Integration Authorities in Scotland.**

Many third sector organisations are commissioned and expected to deliver vital health and social care services to local communities, yet many third sector organisations struggle to secure financial continuity. This can include uncertainties around long-term planning and sustainability as a result of short-term contracts, as well as reduced financial support from statutory partners, but greater expectation on delivery.

There is a recognition and understanding that the third sector and statutory sources will both have fewer financial resources in the future, highlighting a need for greater collaborative working and innovation with all key stakeholders to ensure successful outcomes for communities. This will be even more crucial following the impact of coronavirus. However, this can only be achieved if there are sustainable funding models for the third sector, especially those commissioned by statutory bodies to deliver services.

- **We are calling for a commitment to innovation and sustainable funding by the Scottish Government with minimum three-year contracts between the third sector and statutory partners.**
- **Commissioners to take a strategic, whole-system approach to developing services focused on outcomes and needs of terminally ill people in communities.**

Layton Thompson/Marie Curie

Place of care and death

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-coronavirus patients over the last eight months[21]. There has been an increase in cancer deaths at home, with 1,500 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 800 extra respiratory deaths at home. There has been a significant reduction in hospital deaths for people dying of non-coronavirus conditions at the same time. In normal times, dying at home is where the majority of patients tell us they want to be, therefore we believe this shift could be a positive development.

There have been innovations and service responses to meet this shift. However, there are serious concerns that many terminally ill people and their carers will not have received the care they needed at home during the pandemic. 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.

- **Research and evidence should be carried out to understand the experience of terminally ill people and their carers during the pandemic, to ensure that good practice is identified, lessons are learned, and additional support and resources are put in place to ensure that people get the care they need to maintain this shift of care into the community.**

Hospitals

A third of patients in Scottish hospitals are in their last year of life and 10% die on their current admission[22]. We know that many of these people miss out on the care and support they need when they become terminally ill, are approaching the end of life, and when they die. In 2017/18, 26,917 people in Scotland died in a hospital (47% of all people).

While there are examples of good practice of palliative and end of life care being identified and delivered through acute settings, many hospitals are still not identifying enough patients who could benefit from palliative care. Challenges for this include; IT barriers, failing to meet specialist palliative and end of life care staffing levels, training and education and a 'treat and cure' ethos[23].

As a result, these patients miss out on the end of life support they need and are entitled to[24] and this is likely to have worsened during the coronavirus pandemic from hospitals being under intense pressure. The impact on patients who have missed out on this palliative and end of life support in hospitals will have been distressing, but equally for their families who have had to grieve for their loss in much more isolating circumstances due to the pandemic.

- **Scottish policy and any new palliative care strategy must actively support palliative care in acute settings.**
- **A full range of recommendations for supporting palliative care in acute settings can be found in Marie Curie and the University of Glasgow's report, *Past, present and future caring for those approaching the end of life in Scottish Hospitals*, which was published in 2020.**

Unscheduled care

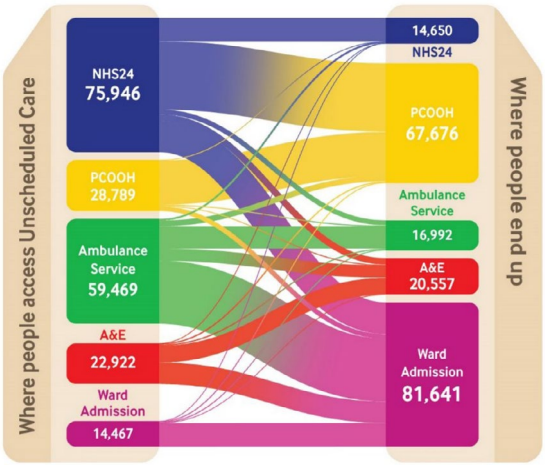
The complexity of terminal conditions means unscheduled and out-of-hours care **(telephone advice, primary care, ambulances, emergency departments and hospital admissions)** is heavily relied on to support those affected by terminal illness, particularly in the final year of life, as conditions worsen and become more unpredictable, with those affected often at breaking point.

University of Edinburgh research, funded by Marie Curie and The Chief Scientist's Office for Scotland, has shown that more than 90% of people in Scotland used unscheduled care five times on average in the last year of life and 34% of all unscheduled care interaction happened in the final month of life[25].

Much of this support has been used by terminally people with multiple health conditions who have unidentified or unmet palliative care needs in the community and inadequate support for informal carers.

The total cost of unscheduled NHS care for people in Scotland for people in their last year of life was nearly £190 million, of which only 3.9% was for provision of primary care services. Innovating care models to better support palliative care delivery in communities could reduce unscheduled care costs, as well as help the majority of terminally ill people to die in their place of choice.

- **We are calling for more investment and development of primary care unscheduled services and NHS 24 to maximise their potential to provide cost-effective unscheduled care for people approaching end of life.**
- **Enhanced data recording and analysis systems at GP practice, board and national level to improve reliable identification of people with palliative care needs and coordination of their care.**

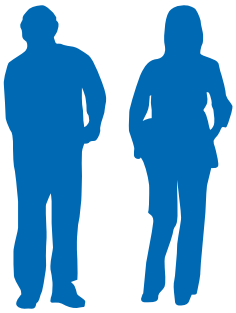


Homelessness

People experiencing homelessness are often denied the right to die well with dignity and face staggering levels of health inequalities, as well as being unable to access palliative and end of life care when they need it; we also know these groups are less likely to ask for help.

Many of those experiencing homelessness have tri-morbidities consisting of a physical condition, mental health issue and alcohol/substance dependency which has a significant impact on quality of life and life expectancy[26] – in Scotland in 2018, the mean age at death was 43 for women and 44 for men[27].

End of life care wishes also remain poorly understood for people experiencing homelessness, though research has shown a fear of needing care and losing control, fear of dying alone, fear of being forgotten and spiritual and practical concerns as common concerns of homeless people at end of life[28]. Similar to the general population, not having early conversations about end of life care wishes in partnership with health and social care practitioners and family/support networks (anticipatory care planning) can result in a more distressing end of life experience.



In Scotland in 2018, the mean age at death was **43 for women and 44 for men**

In Scotland in 2018, there were an estimated 195 homeless deaths, a 19% increase on the estimate of 164 in 2017[29]. Scotland had the highest rate of homeless deaths in all GB countries in 2018 per million population (35.9); this was more than double that of England (16.8) and Wales (14.5). Over half of those deaths in 2018 (53%) were drug related and 8% were alcohol related.

This data[30] suggests that a significant number of people experiencing homelessness will have died with a palliative care need but there is no indication if, or when, they will have received any specialist or generalist palliative and end of life support.

- **The Scottish Government should fully implement the Homelessness and Palliative Care Action Plan published by Marie Curie in 2021.**

In Scotland in 2018, there were an estimated 195 homeless deaths, a **19% increase** on the estimate of 164 in 2017.

Social care

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. Social care can be provided in a person's own home or through a care home.

It 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.

In 2019/20, 88.6% of people in Scotland spent their last six months of life either at home or in a community setting, with 11.4% spending that time in hospital. This is equivalent to an average of 21 days in hospital in the six months prior to death[31].

Over the past 10 years, the percentage of time spent at home or in a community setting in the last six months of life has gradually increased from 85.7% in 2010/11 to 88.6% in 2019/20[32].

However, long-standing fundamental issues in social care in Scotland, including a lack of sustained financial support, workforce challenges and compromised systems, have been exacerbated by the coronavirus pandemic. When combined with a sudden shift towards community deaths since March 2020, coronavirus has significantly impacted the care terminally ill people receive and placed already exhausted workforces under further intense pressure.

Before coronavirus, Marie Curie research projected that by 2040 two-thirds of people will die in community settings but concluded that such a shift in care would not be possible without significant investment in social care.

Marie Curie supports the Scottish Government's recent announcement regarding establishing a National Care Service in Scotland. We believe that this should be an early priority of the new Scottish Government. Alongside colleagues in MND Scotland, Hospice UK and Sue Ryder, we have identified the following key issues which we believe any new national service should address to support those living with a terminal illness:

1. Anticipatory Care Planning: Anticipatory Care Plans are developed as early as possible, and are reviewed regularly, to support early intervention and a proactive care approach to meeting people's changing social care needs.

2. Partnership working: Effective partnership working, information sharing and care co-ordination across statutory, voluntary and independent agencies in health and social care to support the strategic planning, commissioning and delivery of responsive services that meet people's social care needs.

3. Workforce: The social care workforce is supported and valued with sufficient numbers of staff in the right place with the right skills and training to meet the dynamic social care needs of people with terminal or life-shortening conditions.

4. Commissioning: The commissioning and contracting of social care support services to have an agile response to the changing social care needs of people with terminal or life shortening conditions.

5. Care packages: People with terminal or life shortening conditions are assessed for social care packages swiftly and receive their full assessed care package without

delay. These care packages should also include regular carers, flexibility of visiting times and longer visits.

6. Self-directed support: People with terminal or life shortening conditions are supported to access the full range of self-directed support options, if they wish to, including allowing family members to be paid to care, where appropriate.

7. Carers: Informal and family carers of people with terminal or life-shortening conditions are fully supported during and after the caring period, including respite and bereavement support. This should include recognising the financial impact of caring, particularly where many have to reduce working hours or give up their jobs altogether.

Among these issues, there are a number of specifics that we believe need to be addressed. A large proportion of social care models/frameworks are 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. This can have a domino effect throughout the day and cause extensive overtime, much of which is unpaid.

- **We are calling for 15-minute time and task models to be banned and replaced by a strategic commissioning approach which has person-centred outcomes at the heart of delivery.**
- **The Real Living Wage per hour for social care staff should be extended to include overtime.**

Greater investment and support in such approaches and in organisations delivering these services, such as Marie Curie, who could work in partnership with social care services would improve patient outcomes and potentially relieve pressure on social care services.

In some cases, necessary care is simply not available, and people wait for an unacceptably long time to be issued with independence or mobility aids or for care packages to be arranged. Not only do these factors contribute to people having to stay longer in hospital or hospice settings than is necessary, but they can contribute to a worsening of a person's physical, mental or personal situation.

- **There must be a much more rapid response for aids and adaptations for those with a terminal illness.**

Wellbeing has been a long-standing issue in social care workforces, even before coronavirus. There is often limited support available to staff to ensure they can address mental health concerns and issues, and this can lead to staff becoming exhausted, extended sickness absences or even their departure from social care.

- **Accessible emotional support must be available to all care providers which is proactively signposted through Health and Social Care Partnerships and statutory bodies to support social care staff with their mental health, grief and bereavement.**

Supporting digital

Technology has helped innovate palliative and end of life care services during the coronavirus pandemic, allowing a continuity of care and communication between terminally ill patients, their families and carers and health and social care teams.

Remote consultations have become a pivotal, day-to-day part of health and social care services as a result of coronavirus. While they will never replace face-to-face appointments, it is important that technology's role in the future of palliative and end of life care is mapped out to complement existing services.

Marie Curie research into the effect of digital health consultations on our hospice teams, patients and their families during coronavirus has shown:

Benefits:

- An increase in patient choice in how they want to access palliative care services.
- More flexible carer support making clinical advice easily accessible for those caring for someone with a terminal illness.
- New modes of service delivery.

Challenges:

- With relationship building on first assessment.
- Patient/carer communication difficulties.
- Advanced Care Planning where an early relationship had not been established.

Technology should support patient-centred care for terminally ill people through a blended approach with face-to-face appointments and enable those working with patients to have the most up-to-date information about that care and be able to provide appropriate input.

- **The Scottish Government must continue to invest in national digital health innovations to sustain remote consultations and 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.**

While technology has been a lifeline to many, especially throughout the pandemic, there is still a high prevalence of digital exclusion. Minority groups, including ethnically diverse, the elderly and low-income households, in addition to rural communities which have limited or no access to digital devices and/or connectivity, makes establishing and maintaining engagement with palliative care services significantly more complex. It has also led to high levels of isolation and loneliness.

"Most of my clients do not have access to technology or don't know how to use it and, especially during lockdown, this has made them very isolated and has impacted heavily on their mental health. Better access to technology is needed and help with using it." Marie Curie Nurse

Philip Hardman/Marie Curie

Marie Curie research indicates that telephone consultations have been the preferred option of our patients throughout the pandemic, which may be due to patients not having the appropriate technology to facilitate video consultations at home, nervousness about the ease of using video consultations or feeling uncomfortable on camera.

- **As part of the Scottish Government's investment in digital health, training must be included for using digital systems and devices to upskill health and social care workforces, terminally ill patients and their families to increase user confidence.**

While digital training/skills and connectivity is vital, there needs to be greater recognition of issues with access to devices as well as education and upskilling.

- **As part of the suggested Compassionate Community Network initiative, funding should be specifically allocated to support outreach and engagement with minority groups to ensure they can engage with the palliative and end of life support they need.**

Family (informal) carer support

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 recognised[33].

Identifying informal carers to ensure they receive the support they are entitled to can often be difficult and must be improved, as many informal carers do not self-identify as carers or get picked up by formal services and therefore miss out on support and benefits they may be eligible for.

Family carer breakdown is the most likely factor in a person with a terminal illness being admitted to a hospital, hospice or a care home[34]. Having a live-in carer is also the single most important factor in whether someone is able to die at home or not[35].

It has been estimated that an additional 400,000 people took on unpaid caring roles during the first COVID 19 lock down due to health and social care restrictions, taking the total number of unpaid carers in Scotland to around one million[36]. Before coronavirus, the estimated value of unpaid care work in Scotland is £36 billion[37].

Unpaid care in Scotland over the course of the pandemic to date has been valued at £10.9 billion[38] and 3 in 5 of us will become carers at some point in our lives[39].

Evidence from Marie Curie services working during the early part of the pandemic found that many people with family carers were slow to engage with services and often much later at crisis point which caused further challenges.

Latterly, with the greater shift in care into the community and people's own homes. Marie Curie's nursing and community services have been in considerable demand and stretched to capacity, as more and more carers and families have needed support.

- **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 care[40].**

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 well as the projected increase to two-thirds of people dying in community-based settings by 2040.

Marie Curie's report *Life after death: supporting carers after bereavement*, in partnership with Reform Scotland and Sue Ryder, calls for more recognition of the impact of death on the carer and the effect on the carer's physical and mental health, their relationships, their ability to work and their finances:

- **A new Carers (Bereavement Support) (Scotland) Bill should be introduced early in the next Parliament to provide support plans for carers following the end of their caring role.**
- **A new fund should be allocated to support training and education for carers returning to work/seeking employment.**
- **A new Post-Caring Support Payment should be created to help carers struggling financially following the end of their caring role.**

Grief and bereavement

When you lose a loved one, sadness and grief can make dealing with everyday life a challenge. It can be hard to concentrate and make simple decisions.

People experience grief and bereavement at different stages and in different ways, in some cases even starting before the person has died. Grief can also continue for extended periods after someone has died. While the pandemic has acted as a catalyst to improve some support being offered, it previously has not been well recognised or available for people who have experienced a bereavement; this also includes health and social care professionals.

The impact on families can be equally as damaging, with a significant increase in levels of grief and bereavement, as well as more complicated grief, being recorded for those whose family members did not get the palliative support they needed. This has been exacerbated by coronavirus, where lockdown regulations significantly restricted hospital, hospice and care home visiting which caused distress to patients, families and carers and resulted in a lonelier end of life experience for many.

Coronavirus regulations also influenced how people were able to grieve for their loss, which often were in much more isolating environments and will have a lasting physical and emotional impact.

We also know that minority groups are less likely to ask for help, and usually experience more complicated grief as a result of social circumstances than the general population which has been exacerbated during the pandemic.

- **Marie Curie supports the Bereavement Charter for Scotland which champions everyone's right to access the support they need following a bereavement; which will be different for each person.**

Philip Hardman/Marie Curie

Education and training

Training is a vital element of professional development, knowledge and experience building but many health and social care professionals face significant challenges accessing and undertaking palliative and end of life care training. This can result in (early) referral opportunities being missed due to lack of knowledge, and terminally ill patients missing out on the care they need.

A **Palliative and End of Life Care Education and Training Framework** by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support health and social care professionals has been developed, but it is unknown how workforces are performing against the framework's principles and what structure is in place (if any) to ensure consistent training delivery.

Currently, we understand that much of the social care workforce does not currently have palliative and end of life care training, yet is expected to deliver it for patients at home and in care homes.

- **We are calling for a review of health and social care workforces against the NES/SSSC and Palliative and End of Life Care Framework to understand current care delivery and areas for improvement.**
- **The introduction of mandatory palliative and end life care training for all health and social care staff working with terminally ill people to ensure high, consistent standards of care.**

Resource is one of the main obstacles for being unable to release staff for palliative and end of life education and training, which has been exacerbated through the coronavirus pandemic by additional demands on acute settings, primary care and social care.

- **There must be a flexible, ongoing palliative and end of life care education programme established which reflects a blend of face-to-face and digital learning to provide better training for everyone delivering palliative care including families and informal carers.**

Within our education system for young people, there is a wide spectrum of willingness and capability in teachers and staff to talk about dying, death and bereavement in schools, colleges and universities, yet we are still producing a younger generation who are not equipped to be able to handle bereavement, or even to talk about it. The education system must build resilience and support by working to remove taboos around dying, death and bereavement.

- **The Curriculum for Excellence should be reviewed to ensure that talking about dying, death and bereavement is a key component and that teachers across Scotland have the resources and support to engage students in open conversations and discussions about these issues.**

Welfare and benefits

The financial impact of terminal illness on the person affected and their family is often significant. Terminal conditions require a range of support at all levels, especially as they advance, which many people are unable to fund themselves independently.

Easy access to benefits is paramount for terminally ill people, their families and carers to enable them to have as high quality of life as possible. But many people affected by terminal illness do not apply for benefits because they do not know what they are entitled to, they do not think they will be eligible, there is a stigma associated with claiming some benefits and people can be put off by long application processes.

We know that in many cases people affected by terminal illness can be eligible for more than one benefit.

- **We are calling for a simple online application form to be created to support applications for multiple benefits to minimise time spent completing forms and provide a better experience for those applying for multiple benefits.**
- **Easy to read materials should be distributed to accessible locations to ensure essential information is available to help everyone affected by terminal illness understand what they are entitled to and how to claim it.**

As outlined above, informal family carers face considerable financial pressures, both during their caring and following the end of the caring role, particularly when the cared for person has died. We believe that carers should be better supported financially, particularly following a bereavement.

- **Extend eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to six months after the person's caring role comes to an end (from the current eight weeks). Any replacement to Carer's Allowance introduced by the next Scottish Government must continue for at least six months after the death of the cared for person.**

There has been some progress in helping terminally ill people access benefits more quickly and easily. 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 enable the quickest response possible.

However, it will create a two-tier system in Scotland upon its introduction in 2021 – as Universal Credit and Employment and Support Allowance will remain reserved to Westminster.

This could mean that potentially, a person in Scotland may be able to access fast tracked disability benefits but be denied the same if applying for Universal Credit. It will require doctors to use two very different definitions and potentially reach two different conclusions for a person who is terminally ill and wishing to access benefits under the special rules for terminal illness. It will also require doctors and nurses to use two forms, and work with two social security agencies.

- **Marie Curie and our partners are calling for the UK Government to adopt the Scottish Government's definition of terminal illness for all benefits, which will not only lead to a fairer system, but will prevent a two-tier system in Scotland.**

The current economic climate and recession caused by coronavirus has created even greater financial pressures and reliance on social security for some terminally ill people, their families and carers. Carers who were working pre-pandemic may not have been able to throughout the coronavirus pandemic due to being on furlough, have seen a reduction of hours or may have even lost their job. Many may also have been unable to return to work as the terminal condition of the person they are caring for may have deteriorated further throughout the pandemic requiring greater care, which they have been unable to access.

- **The Scottish Government should fund further research to understand what impact the pandemic has had on those caring for someone with a terminal illness at home, and subsequently help inform the role of Scottish Social Security in coronavirus recovery and beyond.**

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