Marie Curie
SCOTLAND

A right to palliative care

Time to fix palliative and end of life care in Scotland

Content

When days are few, they're precious

The number of people dying in Scotland is rising every year; 90% of them need some form of palliative care.[1,2]

Many miss out on the care and support they need because of poverty, where they live, who they are, or what their diagnosis is. Unmet need for palliative care leads to significantly poorer physical and mental health, and financial pressures for people living with a terminal illness, their families, and carers. It also creates avoidable extra demand on Scotland's health and care systems.

Too often, people living with a terminal illness have no choice but to use unplanned emergency care, such as ambulance services and accident and emergency departments, because the palliative care in their community can't meet their needs. Too many people are in hospital at the end of their lives, when they don't need or want to be there.

Marie Curie's vision is of a Scotland where everyone has as much choice as possible about where they die, with care that reflects what matters to them. Scotland should be a country where someone living with terminal illness knows their pain will be treated – somewhere they can be sure that no matter when they need it, compassionate palliative care and support will be available.

We envision a Scotland where carers aren't burdened with worries about how they'll meet the extra costs of their illness and the care that they need.

To get there, the next Scottish Government must legislate to recognise and deliver a right to palliative care for everyone in Scotland.

Liz's story

Liz, 73, struggled to get the palliative care she needed for the terminal lung cancer she was living with. She was estranged from most of her family and lived separately from her partner who had their own care needs.

Liz worried about being alone and not knowing what would happen when she reached the final stage of her illness. At the same time, she was concerned about what would happen to her partner after she died.

"What if I lived in Milngavie and was surrounded by loving sons and daughters that have done really well and had a beautiful house, was a professional person? I suspect my care would be different."

The care package Liz was offered from a home care provider didn't meet her needs, so when she was offered a hospice bed, she took it. Although Liz was happy to be looked after at the Marie Curie Hospice, Glasgow, any real choice about where she wanted to be at the end of her life had been taken away from her.[3]

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Dying is a part of life. At the end of life, it's common for many people to fear the unknown. But they shouldn't fear our health and care systems.

At its best, palliative care wraps around the person living with a terminal illness – and those close to them. It should meet their care needs and bring love and humanity to the end of life, including providing grief and bereavement support.

But not everyone in Scotland gets the palliative care they need.

How and where you live has an impact on how you die. People experiencing financial hardship and deprivation often struggle to access some or all of the palliative care they need.

For rural and island communities, distance often acts as a barrier to accessing palliative care services, while impacting the specialist and generalist workforces who deliver them, including social care professionals. Plus, those with non-malignant conditions are less likely to be identified as having a palliative need than those with a cancer diagnosis.

This is why Marie Curie's top priority for the next Scottish Government is to commit to and legislate to deliver a right to palliative care.

Explicit recognition and implementation of a Right to Palliative Care will help people living with terminal illness, their families and carers, develop an understanding of what they're entitled to, act as a driver for sustainable funding for palliative care and incentivise investment in community and preventative care.

The right needs to be underpinned by Minimum Service Standards to create accountability and clarity for families. A Right to Palliative Care must exist as a right that can be realised.

1. Prioritising palliative care

Health and social care are just as important for people who are dying as for people who aren't.

Across Scotland today, it's not clear who's responsible for ensuring people get the care they need at the end of life. Often, people's palliative and end of life care needs aren't identified until they're in the final stages of their illness. Support is too often only provided once people reach crisis point. Identifying people's needs late means missed opportunities for early interventions – including support from GP or community health and social care teams.

As part of Minimum Service Standards for palliative care, everyone receiving a terminal diagnosis should get an assessment of their palliative and end of life care needs.

People living with a terminal illness, and those close to them, must be informed of and understand what care is available to them – from GP and community nursing care to specialist palliative and end of life care – so they can make informed decisions about their end of life care, and have their wishes adhered to.

Of the £1.3 billion spent on healthcare for people in their last year of life in Scotland, £1.1 billion was to care for them in hospital.[4] In contrast, only 14% of healthcare spend on people in their last year of life was on community care.[5]

Care works best when integration authorities and third sector providers work in partnership. Attaining Minimum Service Standards will look different from place to place and across different care settings, including care homes, hospices, hospitals and people's own homes.

The next Scottish Government must recognise that the contribution of staff in the hospice sector is as crucial to this care delivery as that of their peers in the NHS.

Actions for the next Scottish Government

1. Establish Minimum Service Standards for Palliative Care as part of legislation for a Right to Palliative Care.
2. Commit to pay parity for independent hospice staff with funding uplifts in line with Agenda for Change increases.

2. Accessibility and social care

By 2040, almost two-thirds of all deaths in Scotland will be people dying in community-based settings.[6]

Over this period, the number of people dying with palliative care needs will have increased by 10,000 each year, driven predominantly by people over the age of 85, while the number of people dying with more than one terminal illness will have increased by over 46%.[7]

As a result, more people with more complex needs will require community-based palliative and end of life care. And with higher numbers of elderly people living in rural and island communities, it's clear these areas will see significantly increased demand for palliative and end of life care. The need for 24/7 access to palliative support and a specialist palliative care helpline to make this care accessible has never been more urgent.

As palliative care need increases so too will the need for social care. Social care is a crucial part of the support people living with a terminal illness receive. Yet too much social care is still delivered through an inflexible 'time and task' model which counts the amount of time spent on care rather than how well that care meets people's needs.

Much of the social care workforce also has very little training in palliative care, if any, despite being expected to deliver it in multiple care settings, including care homes.

Actions for the next Scottish Government

1. Create a Scotland-wide specialist palliative care advice and information line on NHS24.
2. Require palliative care training for all staff caring for someone living with a terminal illness – wherever they work including care homes.
3. Ensure social care commissioning meets Minimum Service Standards for palliative care.

Max’s story

For Max, what was important to him at the end of his life was being able to spend time at home with his dog, Lily.

However, Max’s home was unfit for his needs. Living in a fourth-floor flat with a bath he could not climb into made things challenging.[10]

“You see about the stairs, right, the stairs are a big, big problem.”

Because Max wasn’t supported in adapting his home to meet his needs, he couldn’t fulfill his wish to die at home with his dog. His housing circumstances took away the choice that others have. [3]

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3. Housing

Housing insecurity is a significant challenge for people at the end of life.

27,600 people in Scotland each year are forced to move home due to an experience with dying, death and bereavement.[8] Working-age people living with a terminal illness are most at risk of being forced to move home in Scotland due to experiencing terminal illness or bereavement.[9]

Too many people living with a terminal illness face difficulties getting the adaptations that enable them to stay in their homes – and what’s available to them depends on where in the country they live.

Some people living with a terminal illness aren’t even informed they’re eligible for financial support to pay for these adaptations.[11] And too many people are placed on long wating lists to get what they need despite their progressing illness.[12]

Additionally, living in unsuitable accommodation frequently leads to people living with a terminal illness being admitted to hospital – and often dying there.

This problem is worsened by cuts to the aids and adaptations budgets of housing associations and local authorities.

Actions for the next Scottish Government

1. Build increased accessible and social housing to enable people living with terminal illness to live independently.
2. Fully fund existing aids and adaptations budgets for social housing providers to ensure people living with terminal illness have equal opportunity to remain in their homes if they wish.

4. The cost of dying

10,400 people die in end of life poverty every year in Scotland, caused by the costs of living with terminal illness.[13]

Marie Curie and Loughborough University's Dying in Poverty research showed that one in four working-age people, and one in six pensioners, die in poverty at the end of life – an increase of 27% since 2019. One in five people in Scotland also die in fuel poverty at the end of life.[14]

The acute impact of fuel poverty on people living with a terminal illness has also been highlighted in the work of Consumer Scotland, Scotland's statutory and independent body for consumers in Scotland.[15]

Families with dependent children come under huge financial pressure, not only due to the excess costs but also because of the limited capacity of people living with a terminal illness, and their carers, to work as shown in Dying in the Margins, research conducted by University of Glasgow and Marie Curie. Many carers told us they had to reduce working hours or give up their job entirely to fulfil caring responsibilities, resulting in a huge drop in their household income at a time when their bills only increase. In this way, end of life poverty impacts an entire household, not just the person living with a terminal illness.

Unpaid carers provide crucial support not only for their loved one, but also for our health and social care services. Without a live-in carer, it's unlikely someone living with a terminal illness can die at home.

Bereaved carers are particularly vulnerable to falling into poverty. The likelihood of a carer being in poverty increases by 47% after the death of the person being cared for.[16] Currently, bereaved carers continue to receive Carers Support Payment for just 12 weeks after the death of the person they cared for.

Actions for the next Scottish Government

1. As part of a Right to Palliative Care, the Scottish Government must ensure people living with terminal illness have access to adequate income and financial support by committing to and implementing a Minimum Income Guarantee.
2. Extend the Carers Support Payment from 12 weeks to six months following bereavement to enable bereaved families to avoid poverty.

Donna's story

Donna was living with multiple terminal and chronic conditions, including chronic obstructive pulmonary disease. A single parent, she also had caring responsibilities and had experienced a series of bereavements over the last decade, including the sudden death of her son. She also experienced financial insecurity as a result of, and on top of, these hardships.

While Donna received some support from her Community Link Worker, her care wasn't joined up. She feels there are things she hasn't been told by medical professionals, mainly about what she can expect in the future.

"I was thinking the other day, maybe if they actually sat down and told me... about my liver and then my pancreas and all that, they've not really explained how my illness will go on, if you know what I mean? I would like somebody to sit down."[17]

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We have an opportunity

Marie Curie believes that everyone should have the best possible end of life. Crucially, end of life care should reflect what's most important to the individual.

As a society, the care we provide to people reaching the end of life should be as important as the care we provide to people at the start, and throughout, their life. It shouldn't depend on your age, where you live, your income, your housing situation, or your diagnosis.

There's only one chance to get end of life care right. To do that, the next Scottish Government must legislate to recognise and deliver a right to palliative care.

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for further information.

Marie Curie is the UK's leading end of life charity.
Whoever you are, whatever your illness,
we're with you to the end.

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