



**Marie
Curie**
NORTHERN
IRELAND

One chance to get it right

**Now is the time to prioritise
palliative and end of life
care in Northern Ireland**



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Introduction

Everyone in Northern Ireland deserves access to high-quality palliative and end of life care, regardless of where they live, their diagnosis or their circumstances. Yet too many people still face barriers to accessing the care and support they need.

As Northern Ireland prepares for the 2027 Assembly election, there is a crucial opportunity to place palliative and end of life care at the centre of political decision-making. Building on the momentum created by the Health Committee Inquiry into Access to Palliative Care Services¹, this manifesto sets out practical actions that can ensure no one misses out on the support they need during the most difficult time in their life.

Marie Curie is calling on all political parties and independent candidates to commit to four priorities:

- Prioritise palliative and end of life care.
- Prevent crisis situations.
- Ensure no one dies without support.
- Build informed and empowered communities.

These priorities are about creating a society where people can approach death, dying and bereavement with dignity, support and confidence, and where families are not left to face end of life challenges alone.

Why action is needed

Palliative and end of life care provides vital support to people living with a terminal illness and their families. Delivering effective care requires a wide range of services working together across the statutory, independent and community and voluntary sectors.

However, services are not currently reaching everyone who needs them.

It is estimated that one in three people are missing out on the palliative care they need and deserve.

As Northern Ireland's population continues to age, this gap will grow unless action is taken. Northern Ireland has one of the fastest-growing ageing populations in the UK, with the number of people aged over 85 expected to double by 2048.

Northern Ireland is falling behind other parts of the UK and Ireland in how it supports dying people. A lack of investment, particularly in community and out-of-hours services, remains a significant concern.

People are often identified too late for palliative care. Lack of training, inadequate data systems and poor information sharing across services contribute to this problem. Public understanding of palliative care also remains low, creating barriers to access and support.

The next Northern Ireland Executive must build on the findings of the Assembly Health Committee's Inquiry into Access to Palliative Care Services and drive forward meaningful reform.

We urge all political parties and candidates standing for the Assembly election to commit to addressing these longstanding issues as a priority in the next Government. We believe there is a moral imperative to do so.

“My mum was admitted to hospital in September 2023 and it was discovered that she had a ruptured gallbladder and [she was considered] not a candidate for surgery due to her age and dementia. I can only describe the next two weeks or so as the most traumatic time in my life! As a family we felt like mum was just left to die. We watched her waste away with no food or fluids for two weeks.

“Although we had visits from the palliative care team they only worked 9-5, Monday to Friday!! This is disgraceful. This team should be available seven days a week!

“The whole system needs looked at so that other families don't have the same experience as us. It's something I wouldn't wish on another family.

“It was the most undignified death and my lovely mum did not deserve that.”

Anonymous, Northern Ireland

1. Prioritise palliative and end of life care

Demand for palliative care is expected to increase significantly as the population ages and the number of people living with complex and life-limiting conditions grows.

Northern Ireland's last dedicated Palliative and End of Life Care Strategy expired in 2015. Since then, there has been no up-to-date strategic framework to guide workforce planning, service development or investment.

Without a new strategy, there is a risk of increasing variation in access, quality and outcomes across Northern Ireland. Everyone living with a terminal illness should be able to access high-quality care regardless of where they live or their diagnosis.

A new Palliative and End of Life Care Strategy should be based on projected

need over the next 10-15 years and identify the workforce, infrastructure, services and resources required to meet future demand.

There is also a need for stronger accountability. Northern Ireland currently has no statutory requirement to provide a minimum standard of palliative care services. Establishing palliative care as an essential health service, supported by sustainable funding and minimum service standards, would reduce variation and improve consistency of care.

Palliative and end of life care should be recognised as a cross-cutting priority that contributes to better health outcomes, reduced inequalities, stronger communities and improved quality of life.

Actions for the next Stormont government

1. Commit to improving support for people affected by death, dying and bereavement in the Programme for Government.
2. Develop and implement a new Palliative and End of Life Care Strategy covering the next 10-15 years.
3. Base future planning on robust population projections and assessments of need.
4. Establish clear accountability and reporting mechanisms.
5. Introduce legislation mandating the commissioning and funding of minimum service standards and specifications.
6. Ensure sustainable funding arrangements that recognise palliative care as an essential core service.
7. Strengthen collaboration across government, health and social care, local government, hospices and the community and voluntary sector.

2. Prevent crisis situations

Too many people living with a terminal illness experience avoidable crises that result in emergency hospital admissions or attendance at emergency departments.

Many people would prefer to be cared for, and ultimately die, at home or in another familiar community setting. Yet much end of life spending remains focused on hospital-based care.

Earlier intervention and greater investment in community-based palliative care can help people manage symptoms, access timely advice and avoid unnecessary emergencies.

A lack of community provision, particularly during evenings, nights and weekends, means many families feel they have nowhere else to turn when symptoms worsen unexpectedly.

Recent Marie Curie-commissioned research by Queen's University Belfast and Northern Ireland Ambulance Service, and Ulster University painted an alarming picture of the circumstances many people at the end of life find themselves in when seeking help in an emergency.

For people in the last year of life*

8 in 10 people

had at least one ED attendance (81.6%).

59%

of all ED attendances were in the out of hours period.

2 in 3

of all ED attendances resulted in an emergency admission to a hospital ward.

1 in 2

emergency admissions to a hospital ward (via ED or direct admission) were in people aged 80+.

***Source: Marie Curie Northern Ireland (2026) Unscheduled care in the last year of life – Summary of research commissioned by Marie Curie**

Many people approaching the end of life continue to spend precious time in acute settings rather than in their preferred place of care.²

A 2024 Nuffield Report on public expenditure in the last year of life found that, across the UK, approximately 80% of the health budget in the last year of life is spent in acute care – with less than 10% spent on primary or community services.³

Reducing avoidable hospital admissions requires sustained investment in community services, including specialist and generalist palliative care, domiciliary care, care home capacity, step-down beds and effective discharge pathways.

Better co-ordination between ambulance services, GP out-of-hours services, district nursing teams, hospices and wider health and social care services is essential. Expanding hospice at home services and ensuring reliable seven-day, twenty-four-hour support would help more people remain in the place they choose.

By investing in community-based palliative and end of life care, Northern Ireland can create a system that is more proactive than reactive, preventing avoidable crises, improving patient outcomes and ensuring care is delivered in line with people's wishes and needs, as well as reducing pressure on the acute system and delivering efficiencies and financial savings.

Actions for the next Stormont government

- 1.** Ensure comprehensive community-based palliative and end of life care services are available across Northern Ireland.
- 2.** Invest in regional 24/7 palliative care services.
- 3.** Expand out-of-hours clinical support and rapid response services.
- 4.** Increase domiciliary care capacity.
- 5.** Improve access to care home placements and step-down beds.
- 6.** Strengthen integration between ambulance services, GPs, district nursing teams, hospices and health and social care providers.
- 7.** Expand hospice at home services.

3. No one should die without support

The length of time between identification of a palliative care need (or referral) and death varies significantly by diagnosis and age, but the evidence consistently shows many people are referred in the last phase of life. Shockingly, this can be just days or weeks before death.

Evidence shows that early access to palliative care improves symptom management, emotional wellbeing, satisfaction with care and can reduce unnecessary hospital admissions. It enables people and families to plan, make informed decisions and receive care in line with their wishes.

Healthcare professionals must be supported to identify palliative care needs earlier across hospitals, primary care, community services and care homes.

Better coordination between services is equally important. Real-time data sharing, consistent recording systems and improved communication would help ensure people receive joined-up, person-centred support through a Single Point of Access and better signposting and guidance to services available.

Financial hardship is also a significant issue. Around 20% of people in their



last year of life in Northern Ireland are living in poverty.⁴ Falling incomes, caring responsibilities and rising costs can place enormous strain on families already coping with terminal illness.

With stronger collaboration between government, local councils, health services and community and voluntary organisations, people can be connected to welfare support, financial advice and practical assistance earlier.

“My husband could only get access to the hospice two days before his death. It was a great relief when we got home the proper care but an agonising and worrying wait.”

Carol, Strangford

Actions for the next Stormont government

- 1.** Improve the identification, recording and sharing of information relating to people living with a terminal illness.
- 2.** Introduce consistent professional training to support earlier identification of palliative care need.
- 3.** Continue the rollout of Advance Care Planning.
- 4.** Utilise local government and community planning partnerships to support people affected by terminal illness.
- 5.** Ensure people living with a terminal illness have access to adequate income, welfare advice and financial support, including a commitment to implement a Minimum Income Guarantee.
- 6.** Develop targeted measures to address end of life poverty, including support with housing, energy costs and unavoidable illness-related expenses.

4. Informing and empowering communities

It is estimated that one in five people in Northern Ireland are unfamiliar with the terms “palliative care”, “end of life care” and “hospice care”.⁵

Limited understanding of palliative care creates barriers to accessing support. Many people continue to associate palliative care only with the final days of life, despite evidence that earlier access improves quality of life and helps people remain independent for longer.

Greater awareness would empower individuals and families to seek support earlier, understand the options available to them and participate more confidently in decisions about care.

Improving awareness is also important in tackling inequalities. Communities that are less informed about available

services may be less likely to access them.

By encouraging open conversations about death, dying and bereavement, Northern Ireland can build compassionate communities that are better equipped to support people living with terminal illness.

“Marie Curie provided me and my family with vitally important assistance at a time of extreme pressure and sadness for both my father (access to the hospice for his last days) and my mother (overnight nursing at home for her last days).”

Natasha, North Down

Actions for the next Stormont government

1. Develop and implement a public awareness strategy on palliative and end of life care.
2. Support community engagement programmes with councils, hospices and community organisations.
3. Promote earlier conversations about care needs and advance care planning.
4. Ensure information is accessible, culturally appropriate and available to diverse communities.

If not now, when?

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 diagnosis, age, income, where you live or your housing situation.

There is only one chance to get end of life care right.

Now is the time.

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 2. Marie Curie Northern Ireland (2026) Unscheduled Care in Last Year of Life <https://www.mariecurie.org.uk/research-and-policy/research/unscheduled-care-in-last-year-of-life> ; Marie Curie Northern Ireland (2026) Unscheduled care in the last year of life – Summary of research commissioned by Marie Curie. <https://www.mariecurie.org.uk/document/unscheduled-care-in-last-year-of-life>
 3. Nuffield Trust (2025) Public expenditure in the last year of life. <https://www.nuffieldtrust.org.uk/research/public-expenditure-in-the-last-year-of-life>
 4. Marie Curie Northern Ireland (2025) Dying in Poverty 2025: The picture in Northern Ireland. <https://www.mariecurie.org.uk/document/dying-in-poverty-northern-ireland-2025>
 5. <https://www.mariecurie.org.uk/document/creating-a-death-literate-society-ni-2022>

September 2026

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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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