



Care and support  
through terminal illness

# A new deal for people affected by terminal illness in Northern Ireland

Marie Curie Assembly election manifesto 2022





Phil Hardman/Marie Curie

**N**orthern Ireland's population is ageing rapidly, with more and more people living longer with multiple chronic health conditions and complex needs. It's estimated that around 75% of all people would benefit from palliative care before they die<sup>1</sup>, but many people in Northern Ireland face barriers and challenges to accessing this care when they need it.

They may face disparities due to their diagnosis, where they live or where they're being cared for.

Their palliative care needs may not be identified until late in the condition trajectory, with a big impact on their symptom management and quality of life.

Even if their clinical needs are met, they may still miss out on support for the wider social issues – such as access to welfare support and decent housing – that impact so heavily on someone's end of life experience.

The people who matter most to them, including unpaid carers, may struggle to access the support they need to look after their own health and wellbeing and take a break from caring.

And when they die, the loved ones they leave behind may face a bereavement support

system which doesn't have the capacity to meet demand.

These issues haven't been given the attention they deserve on the local policy agenda, but the next Northern Ireland Assembly and Executive have the opportunity to put that right – delivering a new deal for people affected by terminal illnesses in Northern Ireland. In the wake of the Covid-19 pandemic – one of the largest mass bereavement events in recent memory – we have a chance to re-prioritise death, dying and bereavement at the strategic policy level and deliver a palliative and end of life care landscape that's truly fit for the future.

**To help achieve this, Marie Curie is calling on all parties contesting the upcoming Assembly election to pledge to commission a new Palliative and End of Life Care Strategy for Northern Ireland.**

*“No one should pass away in pain, helpless or alone. Every patient needs a hand placed in theirs as they leave this life. This is one thing we all will face ourselves one day. What would you want?” – Joanne*



# A new palliative and end of life care strategy for Northern Ireland

*“End of life care brought my mother and our family and friends huge comfort and support during a very sad and difficult time. It is vital that end of life care is seen as a priority by our Executive and embedded as a right for every citizen.” – Mark*

## **For too long, palliative and end of life care has not been given the attention it deserves at the strategic policy level in Northern Ireland.**

Evidence of this policy inertia is all around. The first draft of the NI Executive’s new Programme for Government Outcomes Framework didn’t say a single word about death, dying or bereavement, while a commitment to fund service improvements in palliative care in the New Decade, New Approach deal has not been fulfilled.

Worst of all, our most recent palliative care strategy – Living Matters, Dying Matters (LMDM) – was published more than 10 years ago. Sufficient resources were never committed to properly deliver the strategy, and even if they had, its five-year life span has long since expired.

Since the strategy became defunct, nearly 50,000 local people with palliative care needs have died<sup>2</sup> – reaching the end of their lives in a very different landscape than existed when LMDM was developed.

*“I have nursed both my parents through the pain of dementia. My sister and I did it together... Is there support? Not really. Help is needed for us all.” – Julia*

Indeed, while the need for strategic change has been recognised in numerous other areas of health and social care – the Bengoa Report, Cancer Strategy, Mental Health Strategy and

Power to People are just a few of the major reviews or strategies that have been commissioned in recent years – palliative care has been left behind.

*“Palliative care is just as important as the beginning of life or any other type of care. It is part of our human rights and should be valued with just as much priority.” – Karen*

This comes against a backdrop of a massive spike in chronic illness and palliative care demand in Northern Ireland. Since 2011, the number of people on the regional Palliative Care Register has doubled,<sup>3</sup> while deaths from cancer, chronic lower respiratory diseases and dementia alone have increased by 10%, 17% and a staggering 65% respectively.<sup>4</sup>

Since 2011, the number of people on Northern Ireland’s Palliative Care Register is up by

**100%**

**50,000**

people with palliative care needs have died in Northern Ireland since the Living Matters, Dying Matters strategy expired

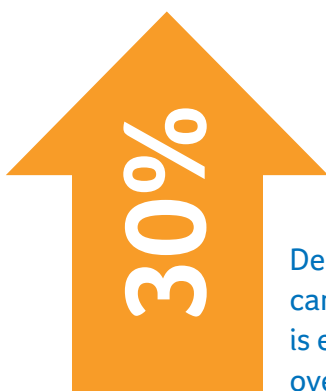


We've experienced a global health pandemic which, among other things, has left over 166,000 people in Northern Ireland impacted by a bereavement<sup>5</sup> – many of whom are living with complicated or prolonged grief because of the circumstances in which their loved one died. And in the years ahead, the NI population is projected to keep getting older and sicker, with demand for palliative care expected to grow by over 30% by 2040.<sup>6</sup>

**Simply put, our next Assembly and Executive need to recognise palliative and end of life care as a strategic policy priority in Northern Ireland.**

*“My husband has terminal cancer... Who will provide support towards the end of his life? How will we be able to ensure he doesn't suffer?... I'm so afraid and worried. This shouldn't be. Life is sacred. People should be allowed to die with dignity and compassion. It is a basic entitlement. Why does our Executive not address this?” – Anne*

We've already fallen badly behind our closest neighbours in this respect. The Irish Programme for Government has seven clear commitments on palliative care and bereavement support – including the development of a new palliative care policy – while every other government in the UK either has a live palliative care strategy in place or has committed to developing one.



Demand for palliative care in Northern Ireland is expected to grow by over 30% by 2040

**It's therefore imperative that the Department of Health commissions and delivers a new palliative and end of life care strategy for Northern Ireland as a matter of urgency after the next Assembly election.**

This strategy should seek to:

- Ensure equitable access to high quality care and support for everyone impacted by death, dying and bereavement; whenever and wherever they need it, and regardless of their diagnosis, age, gender, sexual orientation, socio-economic group or other factors.
- Tackle the wider social and non-clinical issues that heavily impact on someone's end of life experience, including issues like access to welfare support, poverty and housing.
- Reinforce existing programmes to promote public health approaches to palliative care, fostering openness in recognising and planning for death as part of the life cycle across all populations.
- Provide proper support for end of life carers – ensuring they have access to the help they need to maintain their own health, wellbeing and quality of life.
- Develop the necessary infrastructure to record and share data on palliative and end of life needs and outcomes across care settings.
- Deliver high-quality and accessible bereavement support for everyone who needs it.

*“Everyone has a right to palliative care and a dignified passing, both for them and their family... The NI Executive needs to sort this now. There are no excuses.” – Ben*

# References

1. Murtagh, F E et al (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, 28 (1).
2. Based on the number of recorded deaths between 2016-2019 and Murtagh et al (2014).
3. Department of Health. Raw disease prevalence trend data.
4. NISRA cause of death data.
5. Marie Curie (2021). Terminal illness and bereavement during the Covid-19
6. pandemic in Northern Ireland: Perspectives of those left behind and lessons for the future.
7. Palliative Care in Partnership programme



**For more information:**

**Craig Harrison**

Policy Manager Northern Ireland

T: 078724 15059

E: [craig.harrison@mariecurie.org.uk](mailto:craig.harrison@mariecurie.org.uk)