

# A fairer benefits system for all terminally ill people in Northern Ireland

The number of people requiring palliative care in Northern Ireland has risen by at least 250% over the last decade. In the years ahead, our population is set to continue ageing rapidly, with rates of terminal illness also predicted to keep on growing.

When someone is affected by terminal illness, they don't just need high quality care health and social care services – quick and easy access to welfare support can also be vital. The upcoming General Election offers an important opportunity to deliver much-needed change to the benefits system for all terminally ill people in Northern Ireland and the rest of the UK.

To help deliver this, we're calling on all Northern Ireland political parties to pledge to scrap the six-month rule that obstructs terminally ill people from gaining access to benefits unless they can prove they only have six months left to live.

## Scrap the six-month rule

For someone living with a terminal illness, access to welfare support can be a lifeline. Their income may have declined significantly because they're no longer able to work, and they're also likely to be facing huge extra costs for things like equipment and home adaptations, higher heating, energy and travel bills, and specialist food.

*"My mum was diagnosed with colon cancer and given less than twelve months to live. This is a time when you need financial assistance to help with every moment your loved one has left. I know first-hand the frustration and confusion of trying to claw every penny I could – with no success and little help – to still try to give her a decent quality of life; and have been left in financial hardship because of it."*

The welfare system is supposed to provide a safety net during

times like this. However, the current rule, which requires terminally ill people to prove they have six months left to live to get fast track access to benefits, means many people are missing out on the support they need, or facing long waits and huge amounts of red tape to get financial support.

Terminally ill people applying for Universal Credit and Employment and Support Allowance (ESA) are being put through Work Capability



Assessments and made to attend sessions with job coaches to continue receiving their benefits. Those applying for Personal Independence Payment (PIP) are having to wait up to 13 weeks or more to access their payments.

*“My dear mother was in this very position and we only received money after she had passed away. This needs to change so that others in our situation are given the help as soon as they need it.”*

The six-month rule has no clinical or scientific basis – health and social care experts from across Northern Ireland have called publicly for it to be scrapped.<sup>1</sup> By removing the six-month rule from the Westminster statute book and instead trusting doctors and nurses to use their judgement about when someone is terminally ill, we can create a much fairer and more compassionate benefits system for all terminally ill people at minimal cost.

With proper access to benefits, people are better able to heat their homes, afford the food they need and make the adaptations to their home that can help them stay out of hospital at the end of life. A small additional spend in the welfare budget has the potential to deliver huge savings for the Health and Social Care

system in Northern Ireland and across the UK.

Ideally, we would like to see this delivered by local MLAs, but the institutions have not sat for over two-and-a-half years, and terminally ill people cannot afford to wait any longer. In the continued absence of the NI Assembly, we are calling for MPs in Westminster to deliver this much-needed change across the UK.

*“I felt so angry when I was assessed as not fitting the criteria, it’s very disheartening and I just don’t understand why it has to be so difficult. I’m hoping that in the future, things are much easier for people and they can spend time with the people they love most, instead of fighting against an unfair system.”*

Terminally ill people should not have to spend the time they have left fighting for financial support. Scrapping the cruel and unfair six-month rule will help ensure dying people can access the benefits they need, when they need them.

## About Marie Curie

Marie Curie is the leader in the provision of care and support for people with a terminal illness in Northern Ireland. We provide a range of services, including the Marie Curie Hospice, Belfast, Nursing Service and Helper Service. Last year we provided care and support for over 4,400 people living with a terminal illness, and their carers and loved ones.

We’re also the largest charitable funder of palliative and end of life care research in the UK. We campaign to improve access to and the quality of palliative and end of life care, and our ambition is that everybody can access high-quality palliative and social care at the end of their lives; that everybody living with a terminal illness gets the financial support they need, and no-one spends the final days of their lives in unnecessary pain and distress.

## For more information:

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<sup>1</sup><https://www.belfasttelegraph.co.uk/opinion/letters/current-rules-on-deciding-benefits-eligibility-for-terminally-ill-are-unfair-and-need-to-be-reviewed-36982935.html>