

A fairer benefits system for all terminally ill people in Wales

Wales has a rapidly ageing population, with the number of people aged 65 and over projected to increase by 36.6% between 2016 and 2041¹. The rates of terminal illness are also predicted to increase, with more complex conditions and needs than ever before.²

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 Wales and the rest of the UK.

To help deliver this, we are calling on all political parties in Wales 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.

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 are having to wait up to 13 weeks or more to access their payments.

The six-month rule has no clinical or scientific basis – health and social care experts have called publicly for it to be scrapped. 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 Wales and across the UK.

We believe the people of Wales deserve to have access to the benefits they are legally entitled to. We are calling for MPs in Westminster to deliver this much-needed change across the UK.

Terminally ill people shouldn't 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.

Martine Adams, 28, from Barry in Wales, was diagnosed in January 2019 with a diffuse leptomeningeal glioneuronal tumour, a rare cancer of the central nervous system. Martine is married to Scott, who had acute myeloid leukaemia from the age of two and was only discharged last year:

"I remember ringing PIP, pressing the number for terminal because I had been told it was terminal, and the lady on the phone said, 'Hello, have you got six months or less to live?' I said no, and she said, 'Oh, well that's what this is for.' I remember questioning whether I was terminal, and I second guessed it. I spoke to my nurse and she said, 'Yes, it's like Alzheimer's, dementia, MS. They are all terminal illnesses. That's what you've got.' I remember thinking it didn't make any sense – you can't tell someone when they're terminal and then change it, which is what was happening."

About Marie Curie

Marie Curie is the leader in the provision of care and support for people with a terminal illness in Wales. We provide a range of services including the Marie Curie Hospice Cardiff and the Vale and our Nursing and Helper Services. Last year, we provided care and support for over 3,500 people living with a terminal illness in Wales, 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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¹Gweddill.gov.wales. (2019). Welsh Government National population projections.

²Marie Curie (2015) Changing the Conversation.