

A fairer benefits system for all terminally ill people in Scotland

In the next 10 years, more than 500,000 people will die in Scotland. Around 75% of those people will need some form of palliative care at the end of their lives. Urgent action must be taken to improve care and support for people with terminal illnesses to meet the needs of our ageing population.

Marie Curie is the UK's leading charity for people affected by terminal illness. We deliver palliative and end of life care to people across the UK in their own homes or in our hospices.

We are also the largest charitable funder of palliative and end of life care research in the

UK. We campaign to improve access to and quality of palliative and end of life care.

We run a nation-wide information and support service, as well as support for practitioners working to support people with a palliative care need.

Marie Curie in Scotland

Last year, we cared for more than 7,500 people through our nursing services in 31 out of 32 local authorities, our hospices in Edinburgh and Glasgow and the West Lothian Palliative Care service at St John's Hospital, Livingston. We have direct service provision in every Westminster constituency in Scotland.

Our ambition is that everybody who needs high-quality palliative and social care can get access to it, regardless of their personal circumstances; 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. To deliver on this ambition, it's vital that end of life care and social care get the priority they deserve.

Scrap the six-month rule for all benefits for terminally ill people

Last year in Scotland, the Social Security (Scotland) Act devolved disability benefits to Scotland, including Personal Independence Payment (PIP) and Attendance Allowance. People who are terminally ill can access these benefits by a system of special rules, which allow them



to receive the benefits quickly, at the highest amount available and with limited additional assessments.

Marie Curie and MND Scotland successfully campaigned to include in the act a definition of terminal illness that allows clinicians to decide who's terminally ill, for the purposes of accessing disability benefits. This will come into force from 2020.

This replaced the definition of terminal illness previously used by the Department for Work and Pensions (DWP) for these benefits, which stated that a person must be 'reasonably expected' to die within six months before being able to access such benefits.

Advances in diagnosis and treatment mean people are living longer with terminal illness than before, making it harder than ever for doctors to predict how long somebody might live. For those with complex conditions it can be impossible to estimate when somebody has six months to live. The new Scottish definition will enable people with all terminal conditions to access benefits quickly and fairly, not just those who can prove they have six months or less to live.

This definition secured support from all political parties in Scotland as it passed unanimously in the Scottish Parliament.

However, it only applies to the newly devolved disability benefits. Those benefits that remain reserved to Westminster, such as Universal Credit and Employment and Support Allowance (ESA), still follow the DWP rules.

This means that we will face a two-tier system in Scotland, where some people will be able to get all the benefits they're entitled to quickly and others will only get their disability benefits quickly. Some will be forced to wait, go through intrusive and undignified assessments and in some cases, never even get all the benefits they are entitled to.

We know that:

- Many terminal illnesses have very uncertain trajectories, making it hard to know how long someone has left to live. As many as one in four estimates by doctors of how long terminally ill patients have left to live are wrong.
- Between April 2013 and April 2018, 17,000 people in the UK died waiting for a decision on their Personal Independence Payment (PIP) claim – an average of 10 people every day.
- Nearly one third of GPs have never signed a DS1500 for a non-cancer patient.
- 43% of people caring for someone at the end of life say they struggle financially.

We need the DWP to adopt the new Scottish definition so that terminally ill people in Scotland can access all their benefits quickly, in a dignified way and at an amount that will allow them to live as well as possible.

Clinicians, charities, social and palliative care workers and medical experts all support this reform.

We welcome the DWP's recent announcement of a review into how the benefits system treats people living with a terminal illness, but this must go much further.

Marie Curie is calling on the next UK government to scrap the six-month rule in UK benefits law so that everyone with a terminal illness can get fast track access to the benefits they need, preventing a two-tier system in Scotland.

Marie Curie is calling on all MPs to support Madeleine Moon MP's Private Member's Bill, the Access to Welfare (Terminal Illness Definition) Bill 2017-19, in the next Parliament, to implement this reform.

For more information please read the All Party Parliamentary Group for Terminal Illness's report into the six-month rule at mariecurie.org.uk/appg