

# Marie Curie briefing: Social Security (Terminal Illness) Bill

December 2021

## KEY POINTS

- **Marie Curie warmly welcomes the introduction of the Social Security (Terminal Illness) Bill and is calling on all parties to support its Accelerated Passage during the current Assembly mandate.**
- The bill will deliver much-needed reform to the Special Rules for Terminal Illness (SRTI) in social security law in Northern Ireland. The SRTI are supposed to provide fast-track access to welfare benefits for terminally ill people, but the existing eligibility criteria is restrictive and unfairly excludes many dying people. The Bill will help to address that – extending provision of fast-track claims and ensuring many more terminally ill people are able to access the welfare support they need, without facing distressing disability assessments, long delays and unnecessary bureaucracy.
- **Estimates from the Department for Communities suggest the bill will result in 1,010-1,840 more dying people accessing fast-track benefits every year in Northern Ireland – the equivalent, at the upper end, of an 89% increase on the current Special Rules caseload.** <sup>[1]</sup>

## SPECIAL RULES FOR TERMINAL ILLNESS IN SOCIAL SECURITY LAW

1. People living with terminal illnesses can apply for fast-track access to Personal Independence Payments (PIP), DLA, Universal Credit (UC), Employment and Support Allowance (ESA) and Attendance Allowance (AA) under the Special Rules for Terminal Illness (SRTI).
2. The current definition of terminal illness used to determine eligibility for a SRTI claim is: “a progressive disease and death in consequence of that disease can reasonably be expected **within 6 months.**” People claiming under SRTI are encouraged to get a DS1500 medical report to support their claim, which provides information about their condition and current/future treatment.
3. For the limited number of terminally ill people who are currently eligible for social security payments under the Special Rules, the experience is significantly different than for those who aren't:
  - **PIP** – SRTI claimants will not have to complete the ‘How your disability affects you’ form; will not need to attend a face-to-face assessment; will be entitled to the enhanced rate of the Daily Living component of PIP without having to satisfy the normal three month qualifying period; and will have their claim processed, on average, more than six times faster than normal claims (13 weeks vs 2 weeks). <sup>[2]</sup>
  - **Universal Credit** – SRTI claimants will not have to take part in a Work Capability Assessment and will automatically be treated as having limited capability for work-related activity, meaning they will not have to fulfil work requirements to continue receiving their payments.
  - **Employment and Support Allowance** – SRTI claimants will not have to take part in a Work Capability Assessment and will automatically be put in the Support Group without serving the usual 13-week assessment phase.
  - **Attendance Allowance** – SRTI claimants will not have to wait through the usual six-month qualifying period for Attendance Allowance and will automatically qualify for the higher rate.

## WHO IS CURRENTLY BEING EXCLUDED?

4. By using a definition of terminal illness that is tied to a life expectancy of 6 months or less, many legitimate claimants are currently excluded from applying for welfare support under the Special Rules. For many terminal illnesses, particularly non-cancer conditions like motor neurone disease, chronic heart failure and COPD, accurate prognosis can be difficult because of the unpredictable trajectories of these conditions. The rate of progression can vary, and patients may be expected to live for a longer

<sup>1</sup> Department for Communities. [Social Security \(Terminal Illness\) Bill: Section 75 screening form](#). Based on SRTI caseload for DLA, PIP, Attendance Allowance and ESA as at May 2021.

<sup>2</sup> Department for Communities. [Personal Independence Payment statistics – August 2021](#). Latest data available.

period but die within 6 months due to a sudden decline in their condition. **Many terminally ill people are not qualifying for benefits under the Special Rules because their doctor is unable to predict their life expectancy to within 6 months – a restrictive timeframe that has no basis in clinical reality.**

5. The current system is only really working for patients with a predictable disease trajectory, such as some types of cancer. While cancer accounts for less than a third of deaths every year, FOI data shows it has consistently represented between **80-95%** of the local PIP claims awarded under SRTI.
6. Those who are excluded from the Special Rules will have to apply for welfare support under the normal rules. Having to wade through the bureaucracy of the welfare system, fill in extensive paperwork and attend disability assessments causes significant distress for terminally ill people. It also robs them of time that they should be spending making memories with loved ones and getting their affairs in order.

*“The same thing happened to my mum. It put her under even more distress than she was already in after being given a terminal illness diagnosis. I had to speak on her behalf most of the time whilst making phone calls to try and sort everything out as she was in tears and couldn't speak. It was disgusting and the last thing she needed. No one needs that extra stress in their last days, weeks or months of life.”* – Jodi, from Belfast

7. The significant delays associated with standard welfare applications may also mean terminally ill people spending the end of their lives facing severe financial pressures. Being terminally ill is very expensive – any paid employment will be significantly impacted and dying people and their carers will also face extra costs for things like equipment or home adaptations and higher household bills and travel costs. In this context, the financial support provided by the social security system can be a lifeline for terminally ill people and their loved ones, but long delays to access welfare payments are compounding the financial pressures facing many households.

*“A relative was thrust into mortgage arrears waiting on benefits. She had been diagnosed with cancer and had to leave her job. I asked the question: 'are you waiting on a death certificate to prove she has cancer and won't be cured?'"* – Adam, from Fermanagh

8. This delay in accessing payments has a unique impact on terminally ill people because time is a luxury they usually don't have. Delays are meaning that some terminally ill claimants are not receiving their benefits until the advanced or end stages of their condition. They may spend their final weeks and months fighting against the bureaucracy of the social security system, and may even end up dying before they receive their first payment.

*“My brother died waiting and received a letter saying he was fit for work the day of his funeral.”* – Claire, from Lisburn

#### A FAIRER DEFINITION OF TERMINAL ILLNESS

9. The Social Security (Terminal Illness) Bill will extend the life expectancy criteria under the Special Rules from 6 months to 12 months – ensuring thousands more dying people get fast-track access to welfare benefits. This change is much more closely aligned to clinical evidence than the current system – Living Matters, Dying Matters (NI's last palliative care strategy) and NHS England both definition 'end of life' with a 12-month life expectancy. Ireland's HSE also defines 'terminal illness' in the same way.
10. The bill will also change the Special Rules life expectancy criteria in all relevant benefits simultaneously. While the DWP has similarly committed to extending the Special Rules from 6 months to 12 in GB, this will be done on a benefit-by-benefit basis and it could take up to 2 years before the change is delivered for all relevant benefits. That will create a two-tier system, with terminally ill people subject to different rules depending on the benefit(s) they are applying for.
11. **The Social Security (Terminal Illness) Bill will deliver much-needed reform to the Special Rules process and ensure that thousands more dying people in Northern Ireland can access the welfare support they need, when they need it. Marie Curie is calling on all parties to support it under Accelerated Passage.**

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