

Briefing: Special Rules for Terminal Illness in social security law

Marie Curie - January 2021

APPLYING FOR SOCIAL SECURITY WITH A TERMINAL ILLNESS

1. People living with terminal illnesses can apply for fast-track access to social security payments like Personal Independence Payment (PIP), Universal Credit (UC), Employment and Support Allowance (ESA) and Attendance Allowance (AA) under Special Rules for Terminal Illness (SRTI).
2. The legal definition of terminal illness used to determine eligibility for a Special Rules claim is: “a progressive disease and death in consequence of that disease can reasonably be expected **within six months.**” This definition was introduced in Westminster in 1990 and applies in Northern Ireland, England, Wales and for non-devolved benefits in Scotland.
3. People claiming benefits under SRTI are encouraged to get a DS1500 medical report from their GP, consultant or specialist nurse to support their claim. DS1500s provide information about the person’s condition and current/future treatment. If a DS1500 report is not provided, additional medical evidence may be required.
4. Terminally ill people who are eligible for social security payments under the Special Rules are likely to have a significantly different experience than 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). ^[1]
 - **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 (e.g. sessions with Work Coaches) 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 BEING EXCLUDED?

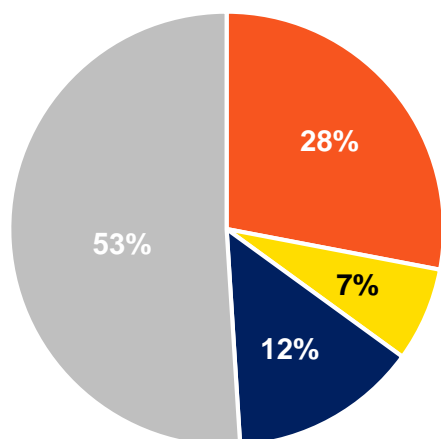
5. Marie Curie believes that, by using a definition of terminal illness that is tied to a life expectancy of six months or less, many legitimate claimants are excluded from applying for welfare support under the Special Rules for Terminal Illness.
6. For many terminal illnesses, particularly non-cancer conditions like motor neurone disease (MND), chronic heart failure and chronic obstructive pulmonary disease (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 period but die within six months due to a sudden decline in their condition.
7. Quantitative evidence reinforces how difficult it is for medical professionals to provide accurate predictions of life expectancy for dying patients. For example, one study into prognostic estimates of life expectancy for over 8,000 palliative patients found that accuracy varied from 23% to 78%. ^[2]

¹ Department for Communities. Personal Independence Payment statistics – August 2020.

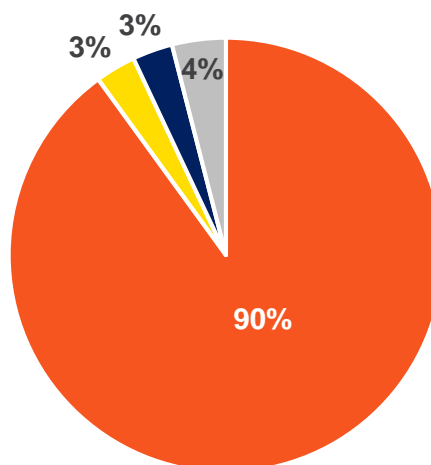
² White, N et al (2016). A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts? *PLoS One*; 11 (8).

8. These factors mean that many people with terminal illnesses may not qualify for benefits like PIP, Universal Credit and ESA under the Special Rules for Terminal Illness because their doctor is unable to predict life expectancy to within six months.
9. The current system is only really working for patients with a predictable disease trajectory, such as some, but by no means all, types of cancer. While cancer accounts for less than a third of deaths every year in Northern Ireland, it accounts for between **80-90%** of the local PIP claims awarded under SRTI,^[3] while other condition types are significantly under-represented in Special Rules awards relative to the number of deaths they account for.

Cause of death N. Ireland 2019



PIP SRTI claims in payment N. Ireland^[3]



■ Cancer ■ Neurological diseases
■ Respiratory diseases ■ All other

THE IMPACT OF THE SIX MONTH RULE

10. 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, getting their affairs in order and doing the things they want to do before they die.

“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

11. 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. Two-thirds of households affected by terminal illness experience financial strain as a result.^[4] In this context, the financial support provided by the social security system can be a lifeline for terminally

³ As at 31 May 2020. Data obtained by Marie Curie via a Freedom of Information request.

⁴ Marie Curie (2019). The cost of dying: The financial impact of terminal illness.

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?’ It is degrading enough to go cap in hand when you have worked all your life.” – Adam

“This happened to my dad and they ended up losing their house just before he died.” – Debbie

12. Time is a luxury that terminally ill people don’t have. Delays are meaning that some dying 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.

“Even though we applied when ultimately mum was right at the end of her life, the paperwork and time delay meant that we did not receive any of the money until after she had passed away. To make matters worse, because some of the payment was for after her death, we got immediate demands to repay the money. Eventually, in light of the circumstances, they waived this payment but only after I had been in correspondence and had phoned several people. Obviously at a time of huge distress this caused a needless extra difficulty for me and the family.” – Frank

“When my late brother took ill, he kept worrying about money. He was self-employed and not a man of means. I was horrified that Universal Credit [assessors] had to visit my dying brother. He passed away waiting on Universal Credit despite great support letters from his palliative team.” – Nora

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

“My father died trying to get it [welfare support] but was deceased when we got the [award] letter.” – Jess

A FAIRER DEFINITION OF TERMINAL ILLNESS

13. Marie Curie is calling for a fairer definition of terminal illness that will allow more dying people to access the financial support they need, when they need it.
14. In Scotland in 2018, the Social Security (Scotland) Act replaced the six month rule with a new system based on clinical judgement. This means that medical professionals will be able to use their clinical judgement to determine when someone is terminally ill for the purpose of applying for benefits under SRTI – rather than being tied to a time limit on life expectancy.
15. Adopting this approach in Northern Ireland would allow more dying people to access welfare payments quickly. This would support people to have a better quality of life during the time they have left and avoid the long delays, intrusive assessments and work requirements associated with many benefits.
16. It is important to note that this policy change is not about widening the basic eligibility criteria for welfare payments. The overwhelming majority of dying claimants who are excluded from applying for benefits under SRTI will still be eligible for payments through the normal rules and in many cases these payments will be backdated to the beginning of their claim. The issue is one of time – ensuring terminally ill people get the financial support they are entitled to as quickly as possible.
17. Aside from the moral arguments, there are also a number of other potential benefits to changing the Special Rules system. Firstly, money will be saved by cutting down on the number of unnecessary face-to-face assessments for dying people. By helping terminally ill people to access the financial support they need, when they need it, we can also ensure that more patients are supported to stay at home comfortably, potentially reducing the avoidable use of public services. For example, the cost to the health service of treating morbidity associated with fuel poverty every year is significant, but this could be reduced by giving dying people timely access to welfare support and alleviating the financial pressures they are under.

SUPPORT FOR CHANGE

18. On 7 June 2018, 60 clinicians, academics and other experts in health and social care from across Northern Ireland wrote an open letter to the *Belfast Telegraph*, calling for the six month rule to be scrapped. ^[5]
19. Walter Rader's independent review of the PIP assessment process in Northern Ireland recommended that the six month rule be replaced with a system based on the judgement of clinicians. ^[6]
20. In July 2019, an inquiry by the All Party Parliamentary Group for Terminal Illness in England concluded that the six month rule is not fit for purpose and recommended that it be replaced with a clinical judgement model. ^[7]
21. On 8 July 2020, Belfast High Court ruled that the difference in treatment for terminally ill welfare claimants who cannot reasonable meet the six month life expectancy criterion is discriminatory and "manifestly without reasonable foundation". ^[8]
22. On 29 July 2020, more than 25 health charities, welfare advice groups and other stakeholders from across Northern Ireland wrote to the Minister for Communities to call for the six month rule to be replaced with a system based on clinical judgement. ^[9]
23. On 6 October 2020, the NI Assembly unanimously passed a motion which called for the Minister for Communities to "immediately bring forward legislation to remove the six month rule, provide guidance to health professionals and adopt a fairer definition of terminal illness". ^[10]
24. On 18 December 2020, the second independent review of the PIP assessment process in Northern Ireland reaffirmed the findings of the Rader review that the 6 month life expectancy criterion for terminally ill claimants should be removed and replaced with a system based on clinical judgement. ^[11]
25. *Back in July 2019, the Department for Work and Pensions launched a UK-wide review of how the benefits system supports terminally ill people. This review is important and DfC officials should be recognised for their efforts to ensure local voices were able to contribute to the evidence-gathering stages. However, 18 months have now passed since the review was launched and the findings are yet to be published. Dying people in Northern Ireland simply do not have any more time to lose before the system is reformed.*

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⁵ 'Current rules on deciding benefits eligibility for terminally ill are unfair and need to be reviewed'. *Belfast Telegraph*, 07.06.18. Available online: <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>.

⁶ Walter Rader (2018). Personal Independence Payment: An independent review of the assessment process.

⁷ Six months to live? Report of the All Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness.

⁸ See <https://lawcentreni.s3.amazonaws.com/McA11286Final-Typed.pdf>.

⁹ See <https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/northern-ireland/scrap-the-6-month-rule-for-terminally-ill-welfare-claimants.pdf>.

¹⁰ NI Assembly Hansard official report: Tuesday 6 October 2020. Available online:

<http://aims.niassembly.gov.uk/officialreport/report.aspx?&eveDate=2020/10/06&docID=310172#2981858>.

¹¹ Marie Cavanagh (2020). Personal Independence Payment: A second independent review of the assessment process.