



Social Security (Special Rules for End of Life) Bill [HL]

HL Bill 2 of 2022–23

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On 24 May 2022, the second reading of the [Social Security \(Special Rules for End of Life\) Bill \[HL\]](#) is scheduled to take place in the House of Lords.

The government committed to introduce the bill in the 2022 Queen's Speech. The bill was not referred to directly in the speech. However, the government made the commitment in the speech's [background document](#). The government said the main purpose of the bill would be:

Amending the definition of terminal illness in existing legislation, so that individuals who are considered by a clinician as having 12 months or less to live (rather than the current six months) can have fast-tracked access to important disability benefits.

The bill would amend the terminal illness definition from six months to 12 months for the following benefits:

- disability living allowance
- personal independence payment
- attendance allowance

Currently, there is no specific welfare benefit available for those with a terminal illness. However, there are rules within the existing welfare system to fast-track the claims of those who meet the definition of being terminally ill. These are known as the '[special rules for terminal illness](#)'. The special rules mean that the Department for Work and Pensions (DWP) can consider claims without the need for a face-to-face assessment. If the criteria are met, benefits are often paid at the highest rate.

In recent years, there has been cross-party support for the principle of changing the special rules from a six-month definition to a 12-month end of life approach. Various charities—including the Motor Neurone Disease Association, Hospice UK, and Macmillan Cancer Support—have campaigned for the change.

In 2019, the DWP announced a review of the special rules. [When the findings were published in 2021](#), the government said it would change the definition of 'end of life' from a terminal diagnosis of six months to one of 12 months. The government said that implementing the changes for disability-related benefits would require primary legislation.

The government has already changed the terminal illness rules to the 12-month definition for universal credit and employment and support allowance. Those changes were made through [secondary legislation and came into effect on 4 April 2022](#).

1. Special rules for terminal illness

If someone is living with a terminal illness, their claim to certain benefits can be fast-tracked without the need for a face-to-face assessment. These are known as the [‘special rules for terminal illness’ \(SRTI\)](#). Eligibility for the special rules often means the claimant is paid benefits at the highest rate.¹

For some benefits, such as universal credit and employment and support allowance, the special rules require that a clinician has provided evidence that the claimant has been diagnosed with 12 months or less to live. For other benefits, the eligibility requirement is currently a diagnosis of less than six months to live.

2. What would the bill do?

2.1 Overview

The bill would amend the special rules to apply a 12-month end of life definition for the following disability-related benefits:

- disability living allowance (DLA)
- personal independence payment (PIP)
- attendance allowance (AA)

In the briefing note accompanying the 2022 Queen’s Speech, the government said that since 1990 when the special rules were first introduced there have been advances in NHS care and treatment which mean that terminally ill people are living longer. Therefore, the government said, “it is right that legislation reflects this”.²

The government said the bill would ensure consistency across the benefits system and align it with the NHS’s 12-month approach to end-of life-care, “which involves clinicians thinking about their patient’s support needs, including financial support”.

2.2 Impact of the bill

The DWP has published [explanatory notes](#) (EN) for the bill and an [impact assessment](#) (IA).

The EN sets out the policy and legal background. It stated that during the DWP evaluation of the special rules for terminal illness, published in 2021 (for more information see section 3: ‘Background’ below), the government received evidence that the six-month rule was “no longer fit for purpose and should be changed”.³ The DWP (the department) had received evidence that:

¹ Department for Work and Pensions, [‘The ‘Special Rules’: How the benefit system supports people nearing the end of life’](#), 6 April 2022.

² Prime Minister’s Office, [‘The Queen’s Speech 2022’](#), 10 May 2022, p 73.

³ [Explanatory notes](#), p 2.

The six-month rule made it difficult for people to access benefits under the special rules where they have a progressive disease that can reasonably be expected to cause the individual's death but where the prognosis is longer than six months or of an uncertain length. This was a particular issue for people with conditions such as motor neurone disease. The department also heard that in some situations the six-month rule was forcing conversations between clinicians and patients about their life expectancy at a time they would not have chosen and which could be difficult and distressing for individuals and their families.⁴

Setting out the legislative background, the EN stated that the bill would amend the six-month end of life definition for the three benefits, which are currently contained in the Social Security Contributions and Benefits Act 1992 for DLA and AA and the Welfare Reform Act 2012 for PIP. The bill would also amend the [Universal Credit, Personal Independence Payment, Jobseeker's Allowance and Employment and Support Allowance \(Decisions and Appeals\) Regulations 2013](#), which currently "make provision about decision-making and appeals in relation to PIP [...] and includes certain provisions which relate to claims made by people who are terminally ill".⁵

On the estimated increase in benefits claims resulting from the bill, the IA stated "once fully implemented, an additional 30,000 to 60,000 people per year across England and Wales may benefit from these changes".⁶ The IA estimated that the bill would result in additional costs to the benefits system totalling £112.4mn by 2026/27, comprising "£68.9mn for AA, £40.5mn for PIP and DLA (working age), £2.5mn for DLA (state pension age) and £0.5mn for DLA (child)".⁷

In terms of non-monetised benefits to the affected claimants, the impact assessment stated:

We anticipate that these changes will improve the quality of life for those approaching the end of their lives, by providing these customers with earlier access to financial support through the benefit system. We also anticipate a social benefit from the redistributive impact associated with these monetary transfers between the Exchequer and DWP customers who are approaching the end of their lives.⁸

2.3 Bill provisions

[The bill](#) has two clauses.

Clause 1(1) would amend section 66 of the Social Security Contributions and Benefits Act 1992, in subsection (2)(a) (meaning of "terminally ill" in relation to attendance allowance and disability living allowance), to replace "6" months with "12" months.

⁴ [Explanatory notes](#), p 2.

⁵ [Explanatory notes](#), p 3.

⁶ Department for Work and Pensions, '[The Social Security \(Special Rules for End of Life\) Bill: Impact assessment to extend the end-of-life definition to 12 months](#)', May 2022, p 7.

⁷ Department for Work and Pensions, '[The Social Security \(Special Rules for End of Life\) Bill: Impact assessment to extend the end-of-life definition to 12 months](#)', May 2022, p 3.

⁸ Department for Work and Pensions, '[The Social Security \(Special Rules for End of Life\) Bill: Impact assessment to extend the end-of-life definition to 12 months](#)', May 2022, p 3.

Clause 1(2) would amend section 82 of the Welfare Reform Act 2012 (rules for personal independence payment in cases where death can reasonably be expected within 6 months), in subsection (4) to replace “6” months with “12” months.

Clause 1(3) would amend regulation 2 of the Universal Credit, Personal Independence Payment, Jobseeker’s Allowance and Employment and Support Allowance (Decisions and Appeals) Regulations 2013 (SI 2013/381), to change the definition of “terminally ill” by substituting the words from “expected” to the end of that regulation with “expected within 12 months”.

Clause 2 would extend and apply the bill to England, Wales and Scotland, and make provision for its commencement.

3. Background

In recent years, a range of charities and campaigners have called for the six-month rule for terminal illness to be relaxed.

In 2018, the Motor Neurone Disease Association and Marie Curie launched the [‘Scrap 6 Months’ campaign](#) to lobby for a change in the rules from six months to 12 months.

In July 2019, the all-party parliamentary group (APPG) for terminal illness published the report [‘Six months to live?’](#), which examined the legal definition of terminal illness. It recommended that the SRTI should be relaxed to provide an open-ended time limit, provided that in the judgement of a clinician a person had “a progressive disease that can reasonably be expected to cause the individual’s death”.⁹

Later that month, [Theresa May’s government announced that it would be reviewing the special rules](#). The then secretary of state for work and pensions, Amber Rudd, committed to “a fresh and honest evaluation of our benefits system so that I can be sure that people who are nearing the end of their life are getting the best possible support”.¹⁰

In 2020, the [House of Commons Work and Pensions Committee raised concerns about how the special rules were supporting those with terminal illnesses during the coronavirus pandemic](#). The committee criticised the timeliness of the DWP’s processing of applications for benefits under the rules. The committee also urged the government to publish the findings of the review into the special rules.

On 8 July 2021, the then DWP minister, Justin Tomlinson, gave an [update on the government’s review in a House of Commons written statement](#). He said that it was the government’s intention to:

Replace the current six-month rule with a 12-month, end of life approach. This will mirror the current definition of end of life used across the NHS and ensure that people receive vital support through the special rules six months earlier than they do now.¹¹

⁹ All-party Parliamentary Group for Terminal Illness, [‘Six months to live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness’](#), 3 July 2019, p 47.

¹⁰ Department for Work and Pensions, [‘Terminally ill benefit claimants deserve a fresh and honest evaluation of the way the system supports them’](#), 11 July 2019.

¹¹ House of Commons, [‘Written statement: Disability benefits’](#), 8 July 2021, HCWS166.

The [findings of the review of the special rules were published by the DWP on 20 July 2021](#). The report stated it had heard evidence “directly from people nearing the end of their lives”, from clinicians and the NHS, and from a range of charities, including: the Association of Palliative Medicine; the British Medical Association; Hospice UK; Macmillan Cancer Support; Marie Curie; and the Motor Neurone Disease Association. The report stated that “strong evidence was received throughout the evaluation that the current six-month rule is not fit for purpose and should be changed”¹². The DWP said this was “a consensus across all the groups we consulted”. The DWP concluded that the evaluation:

Supports a move to a 12-month, end of life approach that mirrors the existing NHS England practice on end-of-life care. This will provide clarity for both claimants and clinicians and ensure that people approaching the end of life do not get conflicting messages from the health and welfare systems. It also maximises the opportunity to improve awareness of the special rules and consistency in their application. This should make it easier for people nearing the end of their lives to access the benefits system through the special rules.¹³

In March 2022, the [government used secondary legislation](#) to amend the definition of terminal illness for universal credit and employment and support allowance from six months to 12 months. Those changes came into effect from 4 April 2022. The [government also confirmed that amending the rules for disability benefits would require primary legislation](#), which it committed to introduce “when parliamentary time allows”.¹⁴

The opposition has supported calls for the six-month rule to be amended. In 2019, when the government review of the special rules was announced, Marsha de Cordova, then Labour shadow minister for disabled people, criticised the delay a review would bring. She said: “the longer the government delays, the more needless suffering and anxiety is inflicted on ill and disabled people with terminal illnesses”.¹⁵

In a House of Commons debate on the terminal illness rules in 2021, Jessica Morden (Labour MP for Newport East) said:

The six-month rule is flawed and urgently needs to change [...] [The] six-month hard deadline is too much to ask of carers and claimants. It creates a completely understandable resistance to applying [for benefits].¹⁶

[Ms Morden had introduced a private member’s bill in 2020](#) which sought to relax the six-month rule.¹⁷ However, it fell at the end of the 2019–21 session.

¹² Department for Work and Pensions, ‘[Findings from the evaluation of the special rules for terminal illness process](#)’, 20 July 2021, p 4.

¹³ Department for Work and Pensions, ‘[Findings from the evaluation of the special rules for terminal illness process](#)’, 20 July 2021, p 5.

¹⁴ House of Commons, ‘[Written statement: Supporting people nearing the end of their lives](#)’, 10 March 2022, HCWS674.

¹⁵ Labour Party, ‘[Review of social security for the terminally ill: Marsha de Cordova responds](#)’, 11 July 2019.

¹⁶ [HC Hansard, 22 February 2022, col 734](#).

¹⁷ UK Parliament, ‘[Welfare \(Terminal Illness\) Bill](#)’, session 2019–21, accessed 16 May 2022.

Insurance expert Katherine Knowles, quoted in the Financial Times following the 2022 Queen's Speech, doubted whether the bill would result in more people receiving benefits at the end of their life. Ms Knowles said:

It is an incredibly negative thing to say to someone—that they will definitely die within 12 months—and specialists tend to caveat their prognosis. Therefore, because of the way in which medical professionals define the 'statistical likelihood' of a person's death, I am doubtful this change will result in more people getting disability payouts.¹⁸

4. Read more

- House of Commons Library, '[Accessing benefits with terminal illness](#)', 1 March 2022
- House of Lords Library, '[Queen's Speech 2022: Welfare and pensions](#)', 5 May 2022
- Department for Work and Pensions, '[New government bill extends end of life financial support](#)', 13 May 2022
- Patrick Butler, '[Benefits claimants suffering under end-of-life DWP rule](#)', Guardian, 9 June 2021

¹⁸ Simoney Kyriakou, '[Queen's Speech 2022: Three things you may have missed](#)', FT Adviser, 10 May 2022.

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