

SOCIAL SECURITY (SPECIAL RULES FOR END OF LIFE) BILL [HL]

EXPLANATORY NOTES

What these notes do

These Explanatory Notes relate to the Social Security (Special Rules for End of Life) Bill [HL] as brought from the House of Lords on 23 June 2022 (Bill 118).

- These Explanatory Notes have been prepared by the Department for Work and Pensions in order to assist the reader of the Bill and to help inform debate on it. They do not form part of the Bill and have not been endorsed by Parliament.
- These Explanatory Notes explain what each part of the Bill will mean in practice; provide background information on the development of policy; and provide additional information on how the Bill will affect existing legislation in this area.
- These Explanatory Notes might best be read alongside the Bill. They are not, and are not intended to be, a comprehensive description of the Bill.

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Overview of the Bill

- 1 The Social Security (Special Rules for End of Life) Bill [HL] will enable people who are thought to be in the final year of their life to get fast-tracked access to Disability Living Allowance (DLA), Personal Independence Payment (PIP) and Attendance Allowance (AA). The measures will amend the definition of end of life in existing legislation, which is based on the claimant having six months or less to live, by replacing it with a new twelve-month definition.

Policy background

- 2 The Department for Work and Pensions (“DWP”) provides fast-tracked access to the benefits system for people who are nearing the end of their lives. The provisions which enable this are known as the ‘Special Rules for Terminal Illness’ (“Special Rules”). Special Rules claims are fast-tracked and a face-to-face assessment is not required. No waiting period is applied, and the claimant is awarded the highest level of, as applicable, AA, the care component of DLA or the daily living element of PIP. Since end-of-life provision was introduced in 1990, eligibility for the Special Rules has been limited to those who have been diagnosed with a progressive disease where their death in consequence is likely to occur within six months (“the six-month rule”).
- 3 When the six-month rule was introduced, many people diagnosed as terminally ill were unlikely to survive for more than six months. Since then, advances in diagnosis and treatment mean that people with an end-of-life prognosis are living longer.
- 4 An evaluation into how the benefits system supports people nearing the end of their lives was conducted and the outcomes were published in July 2021 alongside ‘Shaping Future Support: The Health and Disability Green Paper’. This evaluation heard views from people directly affected by terminal illness, their families and friends, the organisations supporting them and the healthcare professionals involved in their care. Strong evidence was received that the current six-month rule was no longer fit for purpose and should be changed, and there was strong support from healthcare professionals for a twelve-month end of life approach aligned with that taken in the National Health Service (NHS).
- 5 The Department also received evidence that 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.
- 6 The NHS considers people to be approaching the end of their life when they are likely to die within the next twelve months. At this point, clinicians are encouraged to think about the support their patients need, including financial support they may need. By changing to a twelve-month end of life definition and aligning with the NHS definition, this new eligibility rule will provide an opportunity for clinicians to have one holistic conversation about a patient’s support needs at the twelve-month point rather than several.
- 7 Some improvements to the delivery of the Special Rules were made in the course of the evaluation as a result of early feedback from stakeholders, e.g. updated guidance was issued to clinicians on completing the medical evidence form used to support these claims (a factual report about a person’s medical condition and symptoms), and a dedicated GOV.UK page

was updated with information on claiming benefits for those nearing the end of their lives.

- 8 On 8 July 2021, the then Minister of State for Disabled People, Work and Health made a Written Statement to Parliament announcing proposed changes to eligibility. The Statement confirmed the Government's intention "to replace the current six-month rule with a twelve-month, end of life approach. This will mirror the current definition used across the NHS and ensure that people receive vital support through the Special Rules six months earlier than they do now".
- 9 The benefits in scope of this Bill are AA, DLA and PIP. The six-month end of life definition for these three benefits is contained within primary legislation – the Social Security Contributions and Benefits Act 1992 ("the 1992 Act") for AA and DLA and the Welfare Reform Act 2012 ("the 2012 Act") for PIP. In relation to PIP, that definition is also contained within the Universal Credit, Personal Independence Payment, Jobseeker's Allowance and Employment and Support Allowance (Decisions and Appeals) Regulations 2013/381 ("the 2013 Regulations"). Similar changes to the definitions which are used in Universal Credit and Employment and Support Allowance have already been made via secondary legislation. The regulations for these two benefits came into force on 4 April 2022.

Legal background

- 10 AA, DLA and PIP legislation contain special provisions which apply where a claimant is terminally ill.
- 11 Section 66 of the 1992 Act provides that a terminally ill claimant for AA, who makes their claim expressly on the ground of terminal illness, shall be taken to satisfy the day and night attendance conditions and to have done so for the period of six months immediately preceding the date of the claim. As such, a terminally ill claimant is entitled to the highest rate of AA and dispensed from the requirement to satisfy the relevant conditions for a period of six months prior to the date of claim.
- 12 Similar provisions apply in relation to DLA. Section 72(5) of the 1992 Act provides that a claimant who is terminally ill is taken to have satisfied the conditions for the highest rate of the care component of DLA. They are also taken to have satisfied those conditions for a period of three months immediately preceding the date of claim, and for a subsequent period of six months (or less if the claimant's death is expected within the six month period). For the purposes of the mobility component of DLA, where a person is terminally ill, they will still be required to satisfy the conditions in the usual way, save that section 73(12) of the 1992 Act provides that they are exempt from having to demonstrate they meet the relevant conditions for three months prior to the date of the award. Section 82 of the 2012 Act provides that a claimant who is terminally ill, and has made a claim for PIP expressly on the grounds of terminal illness, is entitled to the daily living component at the enhanced rate and is dispensed from the required period conditions. A terminally ill claimant is still required to satisfy the conditions for the mobility component of PIP in the usual way, save that section 82(3) of the 2012 Act provides that they are exempt from having to demonstrate they meet the required period condition.
- 13 The 2013 Regulations make provision about decision-making and appeals in relation to PIP (in addition to Universal Credit, Employment and Support Allowance and Jobseeker's Allowance) and includes certain provisions which relate to claims made by people who are terminally ill. These include making provision regarding when a decision can be revised or superseded on the grounds that the claimant is terminally ill.
- 14 At present a person is considered, for AA, DLA and PIP, to be terminally ill when they are

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expected to die, as a result of progressive disease, within six months. This Bill amends the definition of 'terminally ill' within section 66(2)(a) of the 1992 Act (relating to AA and DLA), section 82(4) of the 2012 Act and the 2013 Regulations (both relating to PIP) so that the timeframe within those provisions is extended from six months to twelve months. The changes made by the Bill will consequently allow a wider class of claimants to benefit from the end-of-life provisions detailed above.

Territorial extent and application

- 15 Clause 2 of the Bill sets out the territorial extent. The Bill will extend and apply to England and Wales and Scotland.
- 16 There is a convention that Westminster will not normally legislate with regard to matters that are within the legislative competence of the Scottish Parliament, Senedd Cymru or the Northern Ireland Assembly without the consent of the legislature concerned.
- 17 The Scotland Act 1998 set out the legislative competence of the Scottish Parliament. Section 29(2)(b) of the Scotland Act 1998 states that reserved matters fall outside of the legislative competence of the Scottish Parliament. Part 2 of Schedule 5 to the Scotland Act 1998 specifies matters that are reserved to the UK Parliament. As originally enacted, this included social security schemes with narrow exceptions. Section 22 of the Scotland Act 2016 amended Part 2 of Schedule 5 of the Scotland Act 1998 to include exceptions to reserved matters, which included disability benefits. Whilst legislative competence for disability benefits transferred in 2016, executive competence transferred on 1 April 2020.
- 18 Agency Agreements were established in April 2020 between the Scottish Government and the DWP to cover an interim period up to 2023. The DWP agreed to continue to deliver the existing DWP, but now devolved, benefits, including taking new claims from Scottish residents, and maintaining existing cases on behalf of the Scottish Government until it had built the capacity and capability to deliver its new disability benefits.
- 19 The effect of these developments is that legislative and executive competence in respect of AA, DLA and PIP has transferred to the Scottish Parliament and Government respectively. The disability benefits, therefore, are devolved to Scotland but are delivered by DWP, via the Agency Agreements, under pre-existing GB wide legislation, on behalf of the Scottish Government. The Scottish Government are in the process of introducing their replacement benefits, with cases being transferred to the replacement benefits when the Scottish Government has appropriate capacity.
- 20 As the competence to make legislation in relation to disability benefits, as they apply in Scotland, has passed to the Scottish Parliament, a legislative consent motion will be required in relation to the Bill as it extends to Scotland.
- 21 Schedule 7A to the Government of Wales Act 2006, and section 3 of the Wales Act 2017, set out a reserved powers model, making clear that social security, pensions and child maintenance remain reserved to the UK Parliament. This position is unchanged since devolution began.
- 22 Whilst social security is a devolved matter in Northern Ireland, parity has long been a guiding principle. The Department for Communities in Northern Ireland has worked closely with DWP officials from the outset of the work to reform the Special Rules. They have already legislated, in the Social Security (Terminal Illness) Act (Northern Ireland) 2022, to introduce the same 12-month approach as DWP. As such, this Bill will restore parity by bringing the GB approach to end of life into line with the approach taken in Northern Ireland.
- 23 If the Government introduces or accepts amendments to the Bill during its passage through

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Parliament which relate to matters within the legislative competence of the Scottish Parliament, Senedd Cymru or the Northern Ireland Assembly, the consent of the relevant devolved legislature(s) will be sought for the amendments.

- 24 See the table in Annex A for a summary of the position regarding territorial extent and application in the United Kingdom.

Commentary on provisions of Bill

Clause 1: Special rules to apply where death expected within 12 months

- 25 Clause 1 will amend the current definition of ‘terminal illness’ (which is normally referred to as ‘end of life’) for three specific disability benefits. This definition determines whether a claimant can make a fast-track claim under the end-of-life provisions within those benefits. Claims made under these provisions are not subject to a face-to-face assessment or waiting periods and receive the highest rate of whichever applies of AA, the care component of DLA or the daily living element of PIP.
- 26 Subsection (1) amends the definition of when a person is ‘terminally ill’ from the current 6-month definition, to a 12-month definition in relation to AA and DLA .
- 27 Subsection (2) amends the definition of when a person is ‘terminally ill’ from the current 6-month definition, to a 12 month definition for PIP.
- 28 Subsection (3) amends the definition of when a person is ‘terminally ill’ in relation to the 2013 Regulations. The amendment provides that the 12 month definition of when a person is terminally ill applies to all benefits covered by the 2013 Regulations, thereby bringing the definition which applies in relation to PIP in the 2013 Regulations into line with the amendment made by subsection (2). The 2013 Regulations already apply a 12 month definition in relation to Universal Credit and Employment and Support Allowance.

Clause 2: Extent, commencement and short title

- 29 Subsection (1) provides that the Bill extends to England and Wales and Scotland.
- 30 Subsection (2) provides that clause 1 of the Bill will come into force on the day appointed in regulations made by the Secretary of State.
- 31 Subsection (3) provides that regulations made under subsection (2) may contain transitional, transitory or saving provision.
- 32 Subsection (4) provides that clause 2 comes into force on the day the Bill receives Royal Assent.
- 33 Subsection (5) establishes the short title of the Act (once passed) as the Social Security (End of Life) Act 2022.

Commencement

- 34 The main provisions in clause 1 of this Bill come into force on the day appointed by the Secretary of State. The remaining provisions come into force on the day on which this Bill is passed as an Act.

Financial implications of the Bill

- 35 Widening the definition of end of life will increase volumes of Special Rules awards across the three benefits in scope of this Bill. The annual cost is estimated to reach an additional £112.4 million paid out in welfare benefits in 2026/27: £68.9 million for Attendance Allowance, £40.5 million for Personal Independence Payment and Disability Living Allowance (Working Age), £2.5 million for Disability Living Allowance (State Pension Age) and £0.5 million for Disability Living Allowance (Child). An Impact Assessment has been provided for this Bill.

Parliamentary approval for financial costs or for charges imposed

- 36 A money resolution is required where a Bill authorises new charges on the public revenue – broadly speaking new expenditure – and a ways and means resolution is required where a Bill authorizes new charges on the people – broadly speaking, new taxation or other similar charges. Since Clause 1 of the Bill would lead to increases in expenditure on AA, DLA and PIP, and expenditure on these benefits is funded by money provided by Parliament, a money resolution is required for the Bill. No ways and means resolution is required.

Compatibility with the European Convention on Human Rights

- 37 Section 19 of the Human Rights Act 1998 requires the Minister in charge of a Bill in either House of Parliament to make a statement about the compatibility of the provisions of the Bill with the Convention rights (as defined in section 1 of that Act).
- 38 In the opinion of the Secretary of State for Work and Pensions the provisions of the Bill are compatible with the Convention rights and she has made a statement to this effect.
- 39 The key Convention right engaged by the provisions in this Bill is the protection of property under Article 1 of Protocol 1 and so Article 14 (prohibition on discrimination) is engaged.
- 40 It is acknowledged that a social security benefit is capable of being considered a possession under Article 1 of Protocol 1. The Government does not consider there will be any interference with Article 1 of Protocol 1 as a result of this Bill.
- 41 For the purposes of Article 14, the Government accepts that a social security benefit is capable of being a possession within the ambit of Article 1 of Protocol 1. The effect of the terminal illness provisions, as amended by this Bill, does mean that there is a difference in treatment between claimants who can reasonably be expected to die within 12 months and those who are expected to live for longer. However, the Government does not consider that individuals who fall into these two groups are in an analogous position.
- 42 In any event, even if the two groups were in an analogous position, any differential treatment would, in the Government's view, be justified. It is legitimate to determine whether a claimant should be treated as being terminally ill based on their life expectancy and 12 months is an appropriate and proportionate point at which to draw the line regarding when a benefit claimant should be treated as being terminally ill for social security purposes, and considerable weight should be given by the courts to the views of the legislature.
- 43 The Bill does not change the overarching approach to determining when a person is considered to be terminally ill for the purposes of the relevant benefits. It retains an approach based on the

person's life expectancy but alters where the relevant line is drawn. The current six-month approach was found to be compatible with Convention rights in the Northern Irish case of *Cox v (1) Department for Communities and (2) Department for Work and Pensions* [2021] NICA 46. The same principles apply in relation to the law as amended by this Bill, and the Government considers that the law as amended by this Bill will be compatible with Convention rights.

Duty under section 20 of the Environment Act 2021

44 The Secretary of State for Work and Pensions is of the view that the Bill as brought over from the House of Lords does not contain provision which, if enacted, would be environmental law for the purposes of section 20 of the Environment Act 2021. Accordingly, no statement under that section has been made

Related documents

45 The following documents are relevant to the Bill and can be read at the stated locations:

- The Social Security Contributions and Benefits Act 1992
[Social Security Contributions and Benefits Act 1992 \(legislation.gov.uk\)](https://legislation.gov.uk)
- The Welfare Reform Act 2012
[Welfare Reform Act 2012 \(legislation.gov.uk\)](https://legislation.gov.uk)
- The Universal Credit, Personal Independence Payment, Jobseeker's Allowance and Employment and Support Allowance (Decisions and Appeals) Regulations 2013
[Decisions and Appeals Regulations 2013 \(legislation.gov.uk\)](https://legislation.gov.uk)
- 'Shaping Future Support: The Health and Disability Green Paper'
[Shaping Future Support - The Health and Disability Green Paper \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)
- Findings from the evaluation of the Special Rules for Terminal Illness
[Evaluation-of-the-special-rules-for-terminal-illness-process](https://legislation.gov.uk)

Annex A – Territorial extent and application in the United Kingdom

Provision	England	Wales		Scotland		Northern Ireland	
	Extends to E & W and applies to England?	Extends to E & W and applies to Wales?	Legislative Consent Motion process engaged?	Extends and applies to Scotland?	Legislative Consent Motion process engaged?	Extends and applies to Northern Ireland?	Legislative Consent Motion process engaged?
Clause 1	Yes	Yes	No	Yes	Yes	No	N/A
Clause 2	Yes	Yes	No	Yes	Yes	No	N/A

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