



## EXPLANATORY NOTES

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### Social Security (Special Rules for End of Life) Act 2022

Chapter 42

£6.90



# SOCIAL SECURITY (SPECIAL RULES FOR END OF LIFE) ACT 2022

## EXPLANATORY NOTES

### What these notes do

These Explanatory Notes relate to the Social Security (Special Rules for End of Life) Act 2022 which received Royal Assent on 25 October 2022 (c. 42).

- These Explanatory Notes have been prepared by the Department for Work and Pensions in order to assist the reader in understanding the Act. They do not form part of the Act and have not been endorsed by Parliament.
- These Explanatory Notes explain what each part of the Act means in practice; provides background information on the development of policy; and provides additional information on how the Act affects existing legislation in this area.
- These Explanatory Notes might best be read alongside the Act. They are not, and are not intended to be, a comprehensive description of the Act.



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## Overview of the Act

- 1 The Social Security (Special Rules for End of Life) Act 2022 enables people who are thought to be in the final year of their lives to get fast-tracked access to Disability Living Allowance (DLA), Personal Independence Payment (PIP) and Attendance Allowance (AA). The Act amends the definition in existing legislation of terminal illness, also referred to as nearing the end of life, which was based on the claimant having six months or less to live, replacing it with a 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 End of Life” (“Special Rules”). For claims made under the Special Rules 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.
- 3 Since end of life provision was first 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”).
- 4 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 many people with an end of life prognosis are living longer.
- 5 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 six-month rule was not 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).
- 6 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.
- 7 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 may need, including financial support. Having a twelve-month end of life definition for the Special Rules in the benefits system, aligned with the NHS definition means that clinicians will have the opportunity to have one holistic conversation about a patient’s support needs at the twelve-month point.

- 8 Some additional improvements to the delivery of the Special Rules were made as a result of the evaluation, for example, 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 created. It includes information on claiming benefits for those nearing the end of their lives.
- 9 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 under the Special Rules. 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".
- 10 The benefits amended by this Act 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

- 11 AA, DLA and PIP legislation contain special provisions which apply where a claimant is terminally ill.
- 12 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.
- 13 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.
- 14 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.
- 15 Prior to the commencement of section 1 of this Act, a person was considered, for AA, DLA and PIP, to be terminally ill when they were expected to die, as a result of progressive disease, within six months. This Act 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 Act allow a wider class of claimants to benefit from the end-of-life provisions detailed above.



## Territorial extent and application

- 16 Section 2 of the Act sets out the territorial extent. The Act extends and applies to England and Wales and Scotland.
- 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. While 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 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.
- 21 While 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 Act restores parity by bringing the GB approach to end of life into line with the approach taken in Northern Ireland.
- 22 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 Act

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

- 23 Section 1 amends the 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.
- 24 Subsection (1) amends the definition of when a person is “terminally ill” from the 6-month definition to a 12-month definition in relation to AA and DLA.
- 25 Subsection (2) amends the definition of when a person is “terminally ill” from the 6-month definition, to a 12 month definition for PIP.
- 26 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.

## Section 2: Extent, commencement and short title

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

## Commencement

- 32 The main provisions in section 1 of this Act come into force on the day appointed by the Secretary of State. The remaining provisions came into force on the day on Royal Assent was received.

## Related documents

- 33 The following documents are relevant to the Act 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/ukpga/1992/6)
  - The Welfare Reform Act 2012  
[Welfare Reform Act 2012 \(legislation.gov.uk\)](https://legislation.gov.uk/ukpga/2012/12)

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- 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://www.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://www.publishing.service.gov.uk)
- Findings from the evaluation of the Special Rules for Terminal Illness  
[Evaluation-of-the-special-rules-for-terminal-illness-process](#)
- Delegated Powers Memorandum  
[Memorandum from the Department for Work and Pensions to the Delegated](#)

## 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?	Extends and applies to Scotland?	Extends and applies to Northern Ireland?
Section 1	Yes	Yes	Yes	No
Section 2	Yes	Yes	Yes	No

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## Annex B - Hansard References

34 The following table sets out the dates and Hansard references for each stage of the Act's passage through Parliament.

Stage	Date	Hansard Reference
<i>House of Lords</i>		
Introduction	11 May 2022	<a href="#">Vol. 822 Col. 23</a>
Second Reading	24 May 2022	<a href="#">Vol. 822 Col. 773</a>
Public Bill Committee	Committee discharged 20 June 2022	<a href="#">Vol. 823 Col. 13</a>
Report	No Report stage	-
Third Reading	22 June 2022	<a href="#">Vol. 823 Col. 236</a>
<i>House of Commons</i>		
Introduction	23 June 2022	Not referenced
Second Reading	08 September 2022	<a href="#">Vol. 719 Col. 452</a>
Committee	08 September 2022	<a href="#">Vol. 719 Col. 472</a>
Report & Third Reading	08 September 2022	<a href="#">Vol. 719 Col. 477</a>
Third Reading	08 September 2022	<a href="#">Vol. 719 Col. 479</a>
Royal Assent	25 October 2022	<a href="#">House of Commons Vol. 721 Col. 247</a> <a href="#">House of Lords Vol. 824 Col. 1465</a>

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## Annex C - Progress of Act Table

35 This Annex shows how each section and Schedule of the Act was numbered during the passage of the Act through Parliament.

Section of the Act	Bill as Introduced in the Lords	Bill as amended in Committee in the Lords	Bill as amended on Report in the Lords	Bill as amended at Third Reading in the Lords
Section 1	Clause 1	Clause 1	Clause 1	Clause 1
Section 2	Clause 2	Clause 2	Clause 2	Clause 2

Section of the Act	Bill as Introduced in the Commons	Bill as amended in Committee in the Commons	Bill as amended on Report in the Commons
Section 1	Clause 1	Clause 1	Clause 1
Section 2	Clause 2	Clause 2	Clause 2

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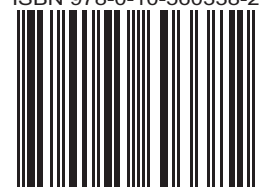
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