

Title: The Social Security (Special Rules for End of Life) Bill: Impact Assessment to extend the end-of-life definition to 12 months Lead department or agency: Department for Work and Pensions Other departments or agencies: Her Majesty's Treasury	Impact Assessment (IA)			
	Date: May 2022			
	Stage: Final			
	Source of intervention: Domestic			
	Type of measure: Primary legislation			
	Contact for enquiries:			
Summary: Intervention and Options				RPC Opinion: Not Applicable

Cost of Preferred (or more likely) Option			
Total Net Present Social Value	Business Net Present Value	Net cost to business per year	Business Impact Target Status
	N/A	N/A	Not a regulatory provision

What is the problem under consideration? Why is government action or intervention necessary?

The Department currently provides support to people who are nearing the end of their life and are expected to have six months or less to live through Special Rules. The Special Rules provide fast-tracked access to Personal Independence Payment (PIP), Disability Living Allowance (DLA), Attendance Allowance (AA), Employment and Support Allowance (ESA) and Universal Credit (UC). Following public and Parliamentary interest, the Department conducted an extensive evaluation of the support the benefits system provides to people nearing the end of their life. There was strong support for the Department to adopt a 12-month approach that aligned with the approach used across the NHS. In the NHS, clinicians are encouraged to identify their patients who are in the final year of life and consider what support their patient requires, including financial support. Switching to a 12-month definition thereby better aligns our approach with that used across the NHS, whilst ensuring the Department can provide fast-tracked financial support to more customers who are approaching the end of their lives.

Note: Equivalent changes for ESA and UC came into force on 4th April 2022. This Impact Assessment relates to the changes for PIP, DLA and AA only.

What are the policy objectives of the action or intervention and the intended effects?

The key policy objectives are: 1) Ensuring thousands more customers nearing the end of their lives can access certain benefits earlier under Special Rules (PIP, DLA, AA), without needing a face-to-face assessment or qualifying period; 2) Aligning the DWP eligibility criteria with the NHS approach where clinicians are encouraged to identify those likely to die within the next 12 months and consider their patient's support needs, including financial support; 3) Having a new, easily understood criterion to support implementation by clinicians and charities who often facilitate access to this support and ensure consistency of approach. This change is expected to come into force in April 2023.

Note: Equivalent changes for ESA and UC came into force on 4th April 2022.

What policy options have been considered, including any alternatives to regulation? Please justify preferred option (further details in Evidence Base)

Option 1: Do Nothing
Do not amend the existing definition. Eligibility to claim under Special Rules remains limited to claimants who are reasonably expected to die within six months as a result of a progressive disease or illness. This would result in an inconsistent approach across benefits as the change to 12-months has already been made for ESA and UC, and with the Special Rules changes that went live across all five benefits in scope in Northern Ireland from April 2022.

Option 2: Change the end of life definition to 12 months instead of six (Preferred Option)
Since the introduction of the Special Rules, there have been considerable medical advances which have changed how people nearing the end of their lives are treated and cared for. There was strong support for the 12-month end of life approach in the Department's evaluation of the Special Rules process. This will ensure more customers nearing the end of their lives can access these benefits earlier, aligning the DWP eligibility criteria with the NHS approach and creating more easily understood eligibility criteria to support implementation by clinicians and charities.

Will the policy be reviewed? It will not be reviewed. If applicable, set review date: N/A				
Is this measure likely to impact on international trade and investment?		No		
Are any of these organisations in scope?		Micro No	Small No	Medium No
What is the CO ₂ equivalent change in greenhouse gas emissions? (Million tonnes CO ₂ equivalent)		Traded: N/A		Non-traded: N/A

I have read the Impact Assessment and I am satisfied that, given the available evidence, it represents a reasonable view of the likely costs, benefits and impact of the leading options.

Signed by the responsible Minister: Christina Date: 11/05/2022

Summary: Analysis & Evidence

Policy Option 2

Description:

FULL ECONOMIC ASSESSMENT

Price Base Year	PV Base Year	Time Period Years	Net Benefit (Present Value (PV)) (£m)		
			Low: Optional	High: Optional	Best Estimate:

COSTS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Cost (Present Value)
Low	Optional	£65.6m in 2026/27	Optional
High	Optional	£186.2m in 2026/27	Optional
Best Estimate		£112.4m in 2026/27	

Description and scale of key monetised costs by 'main affected groups'

These additional welfare payments generate an annual cost to Government which is estimated to reach £112.4m in 2026/27. These costs are expressed as nominal, additional, welfare spending.

Other key non-monetised costs by 'main affected groups'

No non-monetised costs have been estimated.

BENEFITS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Benefit (Present Value)
Low	Optional	£65.6m in 2026/27	Optional
High	Optional	£186.2m in 2026/27	Optional
Best Estimate		£112.4m in 2026/27	

Description and scale of key monetised benefits by 'main affected groups'

The main affected groups are PIP, DLA, or AA claimants with a life expectancy of 6-12 months. Under the proposed change, this group will have fast-tracked access to these benefits, without needing to satisfy any qualifying periods. We assume that the majority of these customers would otherwise claim under Normal Rules and would gain the difference between their award under Normal Rules and Special Rules for the relevant period. The remainder gain the full amount of Special Rules award over the additional duration they receive benefit. The annual benefit is estimated to reach an additional £112.4m paid out in welfare benefits in 2026/27: £68.9m for AA, £40.5m for PIP & DLA (Working Age), £2.5m for DLA (State Pension Age) and £0.5m for DLA (Child).

Other key non-monetised benefits by 'main affected groups'

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.

Key assumptions/sensitivities/risks	Discount rate (%)	N/A
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- **Geographical coverage:** Unless otherwise mentioned, all figures provided for PIP, DLA and AA are at England and Wales level, as these benefits have all been devolved to the Scottish Government. Figures for ESA and UC are at Great Britain level.
- **Volume:** We use DWP data on the timing of deaths in various claimant groups to approximate the volume of additional claimants that hold a relevant prognosis and may become eligible for benefits under the extended end of life definition. We vary the assumption for each benefit in our Sensitivity Analysis.
- **Normal Rules Counterfactual:** Our central estimate assumes 80% of additional awards would otherwise have made a claim under Normal Rules. We vary this assumption (70% - 90%) in our Sensitivity Analysis.
- **Duration:** Because DWP does not carry data on the accuracy of prognoses, we have assumed claimants who are eligible under the new definition spend an additional 6 months on average claiming under Special Rules. We vary this assumption in our Sensitivity Analysis (5 – 7 months).
- **Ramp Up:** We apply an adjustment to the cost profile which reflects a more gradual take-up of the changes. We vary this assumption in our Sensitivity Analysis.

BUSINESS ASSESSMENT (Option 2)

Direct impact on business (Equivalent Annual) £m:			Score for Business Impact Target (qualifying provisions only) £m:
Costs:	Benefits:	Net:	
0	0	0	0

Evidence Base

Problem under consideration and rationale for intervention

Claimants of Personal Independence Payment (PIP), Disability Living Allowance (DLA), and Attendance Allowance (AA) are currently able to make a claim under Special Rules when they are considered by the Department to be nearing the end of their lives by meeting the definition of ‘terminal illness’ contained in legislation. Claimants who claim under Special Rules can access these benefits earlier, without requirements for a face-to-face functional assessment or qualifying period. The majority of Special Rules claimants typically also receive the highest rate of these benefits.

More than 60,000 people in England and Wales are entitled to PIP, DLA or AA under Special Rules, using the current end of life definition (see Table 1).

Table 1: Special Rules Caseloads – PIP, DLA, AA (England and Wales)

Special Rules Caseloads (England and Wales) ¹	
AA (Aug-21)	34,000
DLA (Aug-21)	3,280
PIP (Jan-22)	26,650
Total	63,930

Figures rounded to the nearest 10

The definition of end of life in existing legislation means that only people who a clinician considers have six months or less to live are eligible for fast-tracked access to PIP, DLA and AA. In the NHS, clinicians are encouraged to identify those patients who are likely to die within the next 12 months and to consider their patient’s support needs, including financial support.

In 1990, when the original 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 terminally ill people are living longer. An evaluation into how the benefits system supports people nearing the end of their lives was conducted and published as part of the Shaping Future Support: The Health and Disability Green Paper². 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 throughout the evaluation that the current six-month rule is not fit for purpose and should be changed. This was a consensus across all consultee groups.

DWP received evidence that the six-month rule made it difficult for people with fluctuating conditions or uncertain life expectancy to access benefits under Special Rules. This was a particular issue for people with Motor Neurone Disease. We 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 to do so and which could be difficult and distressing for individuals and their families.

The aim of the Special Rules process is to enable those nearing the end of their life to receive fast-tracked access to benefits. The NHS considers people to be approaching the end of their

¹ Source: DWP [Stat-Xplore](#)

² Source: [Shaping future support: the health and disability green paper - GOV.UK \(www.gov.uk\)](#)

life when they are likely to die within the next 12 months. By changing to a 12-month end of life approach, and aligning with the NHS definition, the DWP ties into the NHS England's long-term plan of improved pro-active, personalised and well-coordinated care for all people in their final year of life. For example, in England there are a number of initiatives in place like the Gold Standards Framework, Daffodil Standards and work led by the Ambitions Partnership for Palliative and End of Life Care to support clinicians, particularly GPs, to identify and care for patients when they are nearing the end of their lives. Clinicians are then encouraged to think about the support their patient needs, including financial support. This then provides an opportunity for the clinician to consider whether their patient should be supported to claim benefits under Special Rules.

The 12-month approach also allows financial support to be provided to people who currently find it difficult under the existing Special Rules criteria such as those with multiple co-morbidities, dying due to organ failure, frailty and dementia. The changes would provide consistency for clinicians when considering those who are in the final year of life across different services that provide support and facilitate a more streamlined process for individuals across the health and welfare systems.

Rationale and evidence to justify the level of analysis used in the IA (proportionality approach)

The proposed change to the eligibility criteria for the Special Rules in PIP, DLA and AA is a positive change for affected customers. The extension will allow individuals in their final year of life to have fast-tracked access to benefits and no customers are expected to be made worse off as a result of this policy. It is difficult to monetise some of the wider benefits of this policy change, however an evaluation into how the benefits system supports people nearing the end of their lives was conducted and published as part of the Shaping Future Support: The Health and Disability Green Paper³. 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 and captures some of the best available evidence about the benefits of the proposed change.

Description of options considered

Option 1: Do Nothing

Do not amend the existing definition. Eligibility to claim under Special Rules remains limited to claimants who are reasonably expected to die within six months as a result of a progressive disease or illness. This would result in an inconsistent approach across benefits as the change to 12-months has already been made for ESA and UC.

Option 2: Change the end of life definition to 12 months instead of six (Preferred Option)

Amend the definition of end of life in existing legislation so that people who have a prognosis of 12 months or less to live are eligible for fast-tracked access to PIP, DLA and AA. This will ensure more customers who are nearing the end of their lives can access these benefits earlier, aligning the DWP eligibility criteria with the NHS approach and creating more easily understood eligibility criteria to support implementation by clinicians and charities.

Estimating the cost of the changes depends upon three key factors:

- Volumes – How many additional people may be awarded a benefit under Special Rules after eligibility changes;

³ Source: [Shaping future support: the health and disability green paper - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/612222/shaping-future-support-the-health-and-disability-green-paper.pdf)

- Duration – How much longer people will spend on benefits under Special Rules because of the change;
- Normal Rules counterfactual – Whether the additional claims who were previously ineligible to claim under Special Rules would have otherwise applied under Normal Rules and what rate of benefit they would have been entitled to.

Volumes:

Widening the definition of end of life will increase volumes of Special Rules awards across AA, DLA and PIP. For everyone who receives a Special Rules award in a given month under the current definition, we assume there will be a group of additional people who would receive a Special Rules award in that month if the eligibility is widened.

We use DWP data on the timing of deaths in various claimant groups to approximate the volume of additional claimants that hold a relevant prognosis and may become eligible for benefits under the extended end of life definition. From this data, we assume that for every individual who is currently awarded each benefit under the current Special Rules definition, there is less than one additional person who would receive an award under the new Special Rules definition⁴. The table below details the impacts this has on Special Rules volumes under a central scenario.

Table 2: Additional Special Rules awards per year – PIP, DLA, AA (England and Wales)

Volume	AA	PIP and DLA (Working Age)	DLA (State Pension Age)	DLA (Child)	Total
Additional Special Rules awards per year	23,000	14,000	2,000	<1,000	40,000

Figures rounded to the nearest 1,000

As it is not possible to claim AA, PIP and DLA simultaneously, these estimates also reflect the total number of individuals expected to benefit as a result of the changes. Our sensitivity analysis estimates that, once fully implemented, an additional 30,000 to 60,000 people per year across England and Wales may benefit from these changes⁵.

Note: Equivalent changes within ESA and UC came into force on 4th April 2022 and are not covered by The Social Security (Special Rules for End of Life) Bill. For information, Table 3 details the impact we estimate these changes will have on additional Special Rules awards under ESA and UC.

Table 3: Additional Special Rules awards per year – ESA, UC (Great Britain)

Volume	ESA	UC
Additional Special Rules awards per year	1,000	4,000

Figures rounded to the nearest 1,000

It is possible to claim ESA/UC in conjunction with disability benefits such as PIP. Therefore, it is not possible to sum these figures with those in Table 2 to get an estimate of total customers

⁴ For example, on PIP over the period April 2013 to January 2018, 57% more claimants died within 0-12 months than 0-6 months of receiving an award. We therefore assume 57% more people will receive an award under the 12-month definition in our Central Scenario. Equivalent assumptions for all benefits are provided in Table 6.

⁵ Figures rounded to the nearest 10,000

affected by the change. Our best estimate suggests 30,000 to 60,000 people per year will benefit as a result of all DWP changes.⁶

Duration:

We assume that everyone newly eligible under the revised definition of end of life gets the highest rate of benefit for an extra six months. In practice, these claimants may not apply on the first day they are eligible or may not live for the further six months. We vary this assumption in sensitivity analysis.

Normal Rules Counterfactual:

We assume the vast majority (80%) of individuals with a 7-12 month prognosis who now claim under Special Rules would otherwise have claimed under Normal Rules. For these claims, we take the difference between the average Normal Rules award and the average Special Rules award as the increase in spend over the six month 'duration' period.

Further, claimants who would have claimed under Normal Rules but are now eligible to make a new claim under Special Rules would have observed a qualifying period where they would not receive benefit for PIP, AA or DLA. Under Special Rules, these claimants would instead receive among the highest levels of benefit during this period. We estimate the additional cost for this group for the relevant qualifying period using the average Special Rules award.⁷

We assume the remaining 20% of claimants with a 7-12 month prognosis who now successfully claim under Special Rules would not have otherwise claimed benefits under Normal Rules. For this group, we assume that the increase in spend is instead equal to the full Special Rules award over the six month 'duration' period.

Take-up and Uprating

Finally, we apply a "ramp-up" adjustment to the estimated annual cost, to reflect a more gradual take-up of the changes. In our Central Scenario, this equates to 33% of the annual cost in Year 1, 67% in Year 2 and 100% by Year 3. We also increase the annual cost each year in line with Consumer Prices Index (CPI) inflation assumptions, to account for anticipated uprating of benefit awards.

Costs

Cost estimates assume changes come into force for PIP, DLA and AA in April 2023. Additional welfare payments commence immediately thereafter. Table 4 shows the estimated costs each year in our Central Scenario, using the assumptions as outlined above.

Table 4: Cost of changes to Special Rules – PIP, DLA, AA (England and Wales)

(£million)	2022-23	2023-24	2024-25	2025-26	2026-27
AA	0	21.6	44.2	67.6	68.9
DLA (Child)	0	0.2	0.3	0.5	0.5
DLA (State Pension Age)	0	0.8	1.6	2.4	2.5
PIP & DLA (Working Age)	0	12.7	25.9	39.7	40.5
Total	0	35.2	72.0	110.2	112.4

⁶ Volumes at England and Wales level for PIP, DLA, AA. Volumes at GB level for ESA and UC. Figures rounded to the nearest 10,000

⁷ For PIP, we also estimate the additional cost of paying Carer's Allowance or Premiums during this period (3 Months) and for AA, we estimate the additional cost of paying Carer's Allowance during this period (6 Months).

Note: Equivalent changes within ESA and UC came into force on 4th April 2022 and are not covered by The Social Security (Special Rules for End of Life) Bill. For information, Table 5 details the impact we estimate these changes will have on costs in ESA and UC.

Table 5: Cost of changes to Special Rules – ESA, UC (Great Britain)

(£million)	2022-23	2023-24	2024-25	2025-26	2026-27
ESA	0.2	0.4	0.7	0.7	0.7
UC	1.2	2.5	3.8	3.9	3.9
Total	1.4	2.9	4.5	4.6	4.6

Summary and preferred option with description of implementation plan

The changes will be given effect through primary legislation (the Social Security (Special Rules for End of Life) Bill) as the current Special Rules applying to PIP, DLA and AA are provided for in primary legislation. There will be no transitional arrangements – the changes will take effect from April 2023 after the Bill has received Royal Assent. Given the staggered implementation of changes to the law (similar changes to UC and ESA take effect from 4 April 2022), there is potentially a year where there are two different definitions of the Special Rules.

Direct costs and benefits to business calculations

We do not anticipate these changes will result in any direct costs or benefits for businesses.

Risks and assumptions

Normal Rules Counterfactual: We vary the assumption around the proportion of additional awards which would otherwise have claimed under Normal Rules between 90%, 80% and 70% (Lower, Central and Higher Scenarios respectively). The percentage of additional awards which would not have otherwise claimed under Normal Rules is therefore set at 10%, 20%, and 30% (Lower, Central and Higher Scenarios respectively).

Duration: Because DWP does not carry data on the accuracy of prognoses, we have assumed claimants who are eligible under the new definition spend an additional 6 months on average claiming under Special Rules. We vary this assumption in sensitivity analysis between 5 months (Lower Scenario) and 7 months (Higher Scenario).

Ramp Up: We apply a ‘ramp up’ assumption to the cost profile, to reflect a more gradual take-up of the changes. In the Central Scenario, this equates to 33% of the annual cost in Year 1, 67% in Year 2 and 100% by Year 3. Ramp up assumptions in the Lower and Higher Scenarios are provided in Table 6.

Volumes: We vary our assumption on the percentage increase in awards made under Special Rules as a result of changing the definition between our Lower, Central and Higher Scenarios. This is estimated using data on deaths for each benefit. Assumptions are specific to each benefit and are outlined in Table 6.

Table 6: Assumptions and Sensitivity Analysis Scenarios

	Lower Scenario	Central Scenario	Higher Scenario
Assumptions for All Benefits			
% of Additional Special Rules Claimants who would have made a normal rules claim	90%	80%	70%
% of Additional Special Rules Claimants who would not have made a normal rules claim	10%	20%	30%
Additional Time Spent on Benefits per Additional Award	5 months	6 months	7 months
Ramp Up per Year	Y1: 25%, Y2: 50%, Y3: 75%, Y4: 100%	Y1: 33%, Y2: 67%, Y3: 100%	Y1: 50%, Y2: 100%
Assumptions for Each Benefit (Additional Awards)			
Attendance Allowance	58% of Special Rules Awards gain additional 5 Months on Special Rules Benefits.	74% of Special Rules Awards gain additional 6 Months on Special Rules Benefits.	100% of Special Rules Awards gain additional 7 Months on Special Rules Benefits.
Disability Living Allowance (Child)⁸	100% of Special Rules Awards gain additional 5 Months on Special Rules Benefits	100% of Special Rules Awards gain additional 6 Months on Special Rules Benefits	100% of Special Rules Awards gain additional 7 Months on Special Rules Benefits.
Disability Living Allowance (Over SPA)⁹	58% of Special Rules Awards gain additional 5 Months on Special Rules Benefits.	74% of Special Rules Awards gain additional 6 Months on Special Rules Benefits	100% of Special Rules Awards gain additional 7 Months on Special Rules Benefits.
Personal Independence Payment & Disability Living Allowance (Working Age)	42% of Special Rules Awards gain additional 5 Months on Special Rules Benefits.	57% of Special Rules Awards gain additional 6 Months on Special Rules Benefits	100% of Special Rules Awards gain additional 7 Months on Special Rules Benefits.

⁸ Due to the relatively small size of Child DLA Special Rules compared to Special Rules for other benefits, we assume 100% of Special Rules Awards gain an additional 5, 6 or 7 months (Low, Central, High) claiming under Special Rules across all three scenarios, a conservative assumption.

⁹ We use the same assumptions as AA for this group.

Table 7: Sensitivity Analysis: Lower and Upper Scenario Costs

(£million)	Scenario	2022-23	2023-24	2024-25	2025-26	2026-27
AA	Lower	0.0	9.5	19.5	29.8	40.5
	Upper	0.0	46.4	95.0	96.9	98.8
PIP & DLA (Working Age)	Lower	0.0	5.4	11.1	17.0	23.2
	Upper	0.0	38.9	79.6	81.2	82.9
DLA (Child)	Lower	0.0	0.1	0.2	0.3	0.4
	Upper	0.0	0.3	0.6	0.6	0.6
DLA (State Pension Age)	Lower	0.0	0.3	0.7	1.1	1.4
	Upper	0.0	1.8	3.7	3.8	3.9
Total	Lower	0.0	15.4	31.5	48.2	65.6
	Upper	0.0	87.4	179.0	182.5	186.2

Monitoring and Evaluation

The Department will engage with stakeholder and clinical groups to ensure that those who meet the new definition are able to claim under Special Rules. We will also monitor existing channels that claimants can use to provide feedback to the DWP.