

Research Briefing

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Social Security (Special Rules for End of Life) Bill [HL] 2022-23



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Summary

The [Social Security \(Special Rules for End of Life\) Bill \[HL\] 2022-23](#) would amend the definition of terminal illness used by the Department for Work and Pension (DWP) and medical professional to fast-track certain benefit claims for people nearing the end of life.

The definition of end of life in existing legislation is based on the claimant having a life expectancy of six months or less. The Bill would replace this with **a twelve-month definition.**

Benefits for terminally ill people

There is no benefit specifically designed to help people cope with the financial impacts of terminal illness. However, there are “Special Rules” the DWP can use to fast-track access to disability benefits where people have a progressive disease, and a medical professional believes their death can reasonably be expected within six months. The benefits are:

- Benefits designed to help with the **extra costs** of disability and ill health – [Disability Living Allowance](#) (DLA), [Personal Independence Payment](#) (PIP), and [Attendance Allowance](#) (AA).
- **Income replacement** benefits for people whose ability to work is affected by disability or ill health – [Employment and Support Allowance](#) (ESA) and [Universal Credit](#) (UC), paid at a higher amount designed to reflect limited capability for work and work-related activity.

Criticism of the six-month rule

This six-month rule has been defined in legislation since 1990. However, it has long come under criticism for being too narrow and for making it difficult for some terminally ill people to access benefits promptly, particularly those with variable conditions where it is difficult for medical professionals to make a clear prognosis.

In recent years there have been campaigns for reform, and the Scottish Government has chosen to adopt an open-ended definition of terminal illness for the [devolved extra-costs benefits](#) it is currently introducing.

DWP evaluation of the terminal illness rules

In July 2019, the then Work and Pensions Secretary, Amber Rudd, launched an [evaluation of the terminal illness rules](#). This considered evidence from claimants, medical professionals and other stakeholders, concluding that the DWP should adopt a twelve-month definition of end of life. This was the most favoured option amongst medical professionals responding to the DWP evaluation and would align the DWP's definition with existing end of life practices used in the NHS.

Implementing the changes

The definitions of terminal illness used for income replacement benefits (Universal Credit and ESA) are in secondary legislation, allowing the Government to adopt the new twelve-month end of life definition for these benefits [through new regulations](#) from April 2022.

For extra-costs benefits, the definition is in primary legislation, requiring a new Act to make the necessary amendments.

Currently, the new definition is already in use for income replacement benefits, but the old six-month rule is still in place for extra-costs benefits. The Social Security (Special Rules for End of Life) Bill will amend primary legislation and align practice across all the relevant benefits.

How many more claims are expected? And at what cost?

The DWP estimates that 30,000 to 60,000 additional Special Rules awards of extra-costs benefits will be made each year in England and Wales after extending the definition to twelve months.

The central estimate is that 40,000 additional claims will be made each year, costing the Government £112.4 million by 2026/27. This is as well as around 5,000 additional annual income-replacement benefit claims, costing £4.6 million by 2026/27.

If the Bill is passed, following Royal Assent, the relevant Secretary of State will need to make regulations for the substantial provisions to come into force. The Government has not announced a target date, but the Bill's [Impact Assessment](#) says the "change is expected to come into force in April 2023."

Northern Ireland and Scotland

The Bill applies in England, Wales, and Scotland. However, [the Scottish Government legislated in 2018 for an open-ended definition to be used](#) for new extra-costs benefits it is currently rolling out.

The [Social Security \(Terminal Illness\) Act \(Northern Ireland\) 2022](#) has already received Royal Assent in Northern Ireland, applying the new twelve-month end of life rules across all relevant benefits from April 2022.

1 Introduction

The [Social Security \(Special Rules for End of Life\) Bill \[HL\] 2022-23](#) (Bill 118 of session 2022-23) was first introduced in the House of Lords on 11 May 2022 as (HL Bill 2). It amends the definition of terminal illness used to fast-track access to benefits designed to help with the extra costs of disability or ill health.

The Bill enacts changes proposed in an [evaluation of the Special Rules for Terminal Illness process](#) published by the Department for Work and Pensions (DWP) on 20 July 2021.

It was introduced in the Lords on 11 May 2022 and had its Second Reading on 24 May 2022. The House of Lords Library produced [a briefing on the Bill](#) in advance of Second Reading. Third Reading took place on 22 June 2022, and the Bill was introduced in the House of Commons the following day. It is scheduled to complete its remaining Commons stages on 8 September 2022.

[The Bill and related publications](#) are available on the UK Parliament website. This includes Explanatory Notes (Bill 118-EN 2022-23) which provide background and commentary on the provisions, an Impact Assessment outlining how many people are likely to be affected and how much the changes might cost, and a Delegated Powers Memorandum produced by the DWP. The House of Lords Delegated Powers and Regulatory Reform Committee said there was nothing in the Bill to draw to the attention of the House.

The Bill will extend and apply across Great Britain. On 29 June 2022, the Scottish Parliament agreed a [legislative consent motion](#), indicating that it is content for the UK Parliament to legislate on a devolved matter. However, the UK Government benefits the Bill applies to are being replaced in Scotland by new [Disability Assistance](#) benefits, for which an open-ended definition of terminal illness is being used.

Equivalent legislation in Northern Ireland, the [Social Security \(Terminal Illness\) Act \(Northern Ireland\) 2022](#), has been in force since 4 April 2022.¹

¹ [The Social Security \(Terminal Illness\) \(2022 Act\) \(Commencement\) Order \(Northern Ireland\) 2022](#)

2 Background

The House of Commons Library has an existing briefing on [Accessing benefits with terminal illness](#).² This covers the history and issues surrounding the definition of terminal illness, how people have applied for benefits under the Special Rules,³ and recent reforms across the United Kingdom.

2.1 Benefits available to terminally ill people

Terminal illness requires people and their families to adapt to their conditions, and to make the most of their remaining time. As well as direct implications of ill health and death, there can be significant financial costs – loss of income, additional costs of care, and the need for other adaptations.

There is no benefit specifically designed to help people who are terminally ill cope with these financial impacts. Provided they meet the eligibility criteria, terminally ill people and their families can access the same social security benefits as the rest of the population. However, there are rules in place which allow simpler and faster access to two kinds of benefits:

- Benefits designed to help with the **extra costs** of disability and ill health:
 - [Disability Living Allowance](#) (DLA) for children under 16.
 - [Personal Independence Payment](#) (PIP) for people of working-age.
 - [Attendance Allowance](#) (AA) for those of State Pension age.
- **Income-replacement** benefits for working-age people whose ability to work is affected by disability or ill health:
 - [New Style Employment and Support Allowance](#) (ESA) for people of working-age who have made sufficient National Insurance contributions.
 - [Universal Credit](#) (UC), a benefit for low-income households which can include an extra amount where a claimant’s capability for work is affected by their disability or health condition.

² [Commons Library briefing CBP-8995](#)

³ The term “Special Rules” is not used in Universal Credit, but the fast-tracking rules relating to terminal illness are comparable to those for other DWP benefits.

Why Special Rules are needed

Accessing disability benefits can be burdensome and time consuming due to claims and assessment processes, and when a person does meet the eligibility criteria for benefit a waiting or qualifying period must usually be served before payment of the full amount begins.

Assessments under the normal rules can take months from the point of application. For instance, the median end-to-end clearance⁴ for Work Capability Assessments (WCAs), usually required to access ESA,⁵ was 141 days in December 2021.⁶ New PIP claims under the normal rules had similar clearance times of 20 weeks in April 2022.⁷

People who qualify for the Limited Capability for Work-Related Activity (LCWRA) element in Universal Credit normally have to serve a three-month ‘waiting period’ before it is included in their maximum amount. People claiming ESA must also normally wait around three months before they are entitled to the additional Support Component, and until then are only paid at the lower [assessment rate](#).

Extra-costs benefits also have “qualifying periods” which require claimants to show they have satisfied the conditions of the benefit for a period before entitlement begins. For example, under normal rules, PIP applicants must satisfy a [qualifying period](#) of three months before entitlement can start. Applicants must normally have had care or supervision needs due to disability or illness [for at least six months](#) before getting Attendance Allowance.

2.2

The existing “six-month rule”

History of the definition

The Special Rules the Bill is amending have been built around a definition of terminal illness first stipulated as an amendment to Attendance Allowance legislation in section 1 of the Social Security Act 1990:

a person is “terminally ill” at any time if at that time he suffers from a progressive disease and his death in consequence of that disease can reasonably be expected within 6 months.⁸

⁴ The period between registering an ESA claim and an award decision being made.

⁵ A WCA is usually also required to access the Limited Capability for Work Related Activity (LCRWA) element in UC.

⁶ DWP, [ESA: Work Capability Assessments, Mandatory Reconsiderations and Appeals: June 2022](#), 9 June 2022

⁷ DWP, [Personal Independence Payment: Official Statistics to April 2022](#), 14 June 2022

⁸ Section 1(2C) of the [Social Security Act 1990 \(as enacted\)](#)

Attendance Allowance is now a benefit for people of State Pension age who need help with personal care or supervision because of illness or disability. In 1990 it was available to any qualifying person aged two or over.⁹

Attendance Allowance has always had a [qualifying period](#), requiring a claimant to show they have satisfied the disability conditions for at least six months before the first day of entitlement. The practical result of this was that a terminally ill person might die before they became entitled to benefit, or before the outcome of their claim was determined. At the time, politicians across Parliament expressed concern that action should be taken to protect those who might die within six months of their diagnosis. The Social Security Advisory Committee recommended the qualifying period be waived.¹⁰

When introducing the definition, Nicholas Scott, the then Minister of State for Social Security, stated the Government had “consulted widely with organisations outside the House about the definition of “terminally ill” and the special arrangements in the clause and they welcomed these proposals”.¹¹

Speaking in a Standing Committee in 1990, Mr Scott added that the intention was to help people likely to die before the end of the qualifying period. Responding to an amendment which would have extended the definition to two years, he emphasised the six month qualifying period:

In essence, the six-month period came about not because of its commonality with the waiting period, although that was one of the factors, but because most of our expert advice was that the majority of people die within three months and that virtually all die within six months, whether or not they have been diagnosed as having a progressive disease with terminal illness in prospect. There is a logical link with the waiting period, so the amendment that would extend the six months to two years is unnecessary.¹²

While this suggests there were other considerations, the main reason six months was chosen appears to have been removing the qualifying period. Interventions in Parliament and parliamentary questions from both Government and opposition MPs calling for special arrangements referred to concerns about the six-month qualifying period in Attendance Allowance.¹³ Debating the Bill, Tony Newton, the then Secretary of State for Social Security, made a firm commitment to “tackle the problems faced by terminally ill people who satisfy the eligibility criteria for attendance allowance, but who die before the six-month qualifying period is complete.”¹⁴

⁹ See regulation 7 of [The National Insurance \(Attendance Allowance\) Regulations 1971, SI 1971/621 \(as made\)](#). Subsequent introductions of Disability Living Allowance (1992) and Personal Independence Payment (2012) have meant that children, working aged adults and pension aged adults are eligible to claim different extra-costs disability benefits.

¹⁰ Quoted in Social Security Advisory Committee, *Benefits for Disabled People: A Strategy for Change*, November 1988

¹¹ SC Deb (G) 1 February 1990

¹² As above

¹³ For example see [HC Deb 6 Feb 1989 c490](#) and [HC Deb 6 March 1989 c585](#)

¹⁴ [HC Deb 22 January 1990 c629](#)

A report published by the Industrial Injuries Advisory Council in 2014 commented the definition of terminal illness employed in the Special Rules “was pragmatically based on a benefit waiting time, rather than scientific evidence”.¹⁵ Replying for the Government in a debate on Universal Credit and Terminal Illness on 9 May 2018, the then Minister for Disabled People, Work and Health, Sarah Newton, said six months “strikes around the right balance”:

We understand that this is not an exact science, and there is much debate among medical professionals about this. We do not ask claimants to give us evidence of their life expectancy, so terminally ill claimants may well remain on benefits for longer than six months. For example, with personal independence payments, around 40% of terminally ill claimants remain on benefits for longer than a year. We take a pragmatic, person-centred approach to these decisions. These rules were first introduced in 1990. We have regular conversations with the medical profession, and we want to ensure that people are given an absolute guarantee of the financial support that they and their families need and that their claims are handled swiftly to reduce the burden on individuals.

Having listened to the medical profession, we understand that six months strikes about the right balance between providing the support that people need and confidence in the prognosis, because the longer the prognosis, the less likely it is to be accurate. Making the period longer than six months would therefore make the diagnosis, and potentially the conversation between doctor and patient, that much more difficult. The Department works very closely with doctors and clinicians, and we are always looking for ways to improve the experience for any of our claimants and for any of our benefits.¹⁶

However it came about, the definition was subsequently adopted for other disability benefits, and has survived for more than three decades, pending the implementation of announced changes.

Adopting the six-month rule in other benefits

Disability Living Allowance replaced AA for people under 65 in 1992, retaining the terminal illness definition.¹⁷ DLA was replaced for people of working-age by PIP from 2013.¹⁸

The definition was later used to allow terminally ill people fast-tracked to access Incapacity Benefit,¹⁹ and was subsequently replicated in Employment and Support Allowance²⁰ and in Universal Credit.²¹

¹⁵ Industrial Injuries Advisory Council, [Terminal Cancers and Industrial Injuries Disablement Benefit](#), April 2014, Cm 8846, para 33

¹⁶ [HC Deb 09 May 2018 cc867-8](#)

¹⁷ Sections 66(2) and 72(5) of the [Social Security Contributions and Benefits Act 1992](#)

¹⁸ Section 82(4) of the [Welfare Reform Act 2012](#)

¹⁹ See [HC Deb 24 January 1994 c41](#) and section 2 of the [Social Security \(Incapacity for Work\) Act 1994](#)

²⁰ Regulation 2 of [The Employment and Support Allowance Regulations 2008, SI 2008/794 \(as amended\)](#)

²¹ Regulation 2 of [The Universal Credit Regulations 2013, SI 2013/376 \(as amended\)](#)

How the existing Special Rules work

Section 3 of the Commons Library briefing [Accessing benefits with terminal illness](#) explores the process of applying under the old Special Rules in detail.

The 1990 legislation also established entitlement of terminally ill people, and the most common mechanism for applying under the special rules – getting a healthcare professional such as a GP to complete a factual DS1500 form confirming that someone with a terminal diagnosis meets the definition.²²

If criteria are met, the Special Rules can allow people to access benefits within days. PIP claims made under the Special Rules were cleared in an average of three days as at the end of January 2022.²³ A person who qualifies²⁴ will usually automatically receive the following rates of benefits:

Benefit	Eligible new claimants	Terminal illness entitlement/level of award
Disability Living Allowance (DLA)	Children under the age of 16	Highest rate care component
Personal Independence Payment (PIP)	Adults aged 16 or over who have not reached State Pension age	Enhanced rate daily living component
Attendance Allowance (AA)	Adults over State Pension age	Higher rate
New Style Employment and Support Allowance (ESA)	Adults under State Pension age with a disability or health condition that affects their capability for work ²⁵	Support Group/Support Component
Universal Credit (UC)	Adults under pension age with a disability or health condition that affects their capability for work ²⁶	Limited Capability for Work-Related Activity (LCWRA)/LCWRA element

²² See sections 2 and 3 of the Commons Library briefing CBP-8995, [Accessing benefits with terminal illness](#)

²³ [PQ149375, 6 April 2022](#)

²⁴ Claimants still have to meet other eligibility criteria, and certain exclusions remain such as for persons subject to immigration control.

²⁵ New ESA claims will be for contributory “New Style” ESA, which is available for people with a disability or health condition that affects their capability for work and have also paid sufficient National Insurance contributions over the last 2-3 years. Claimants who might previously have applied for income-related ESA, which does not depend on National Insurance contributions, but which is means-tested, will now apply for Universal Credit.

²⁶ In mixed-age couples (one under, one over State Pension age) the partner above SPA may be awarded the LCWRA element.

Criticisms of the six-month definition

The definition, which restricts access to the special rules to those who can “reasonably be expected” to die within six months, has been criticised by campaigning groups and politicians. The central complaint is that the definition is too narrow, meaning many people who are terminally ill cannot qualify – particularly those with conditions other than cancer.

For some terminal conditions, the length of survival can be very variable, making it difficult for any medical professional to predict whether a person can reasonably be expected to die within six months. For instance, Motor Neurone Disease (MND), a progressive disease which leads to death, has symptoms and prognoses which can vary significantly from person to person.

The MND Association points out that “MND is a terminal condition with a median survival of 2-3 years, and a third of people will die within a year of their diagnosis, it affects every patient differently and progresses at very different rates. It is not possible for even the most experienced clinician to give a precise prognosis for a person living with MND.”²⁷

Prognostic uncertainty is not limited to MND and applies to a wide variety of terminal conditions. A review of the Liverpool Care Pathway²⁸ in 2013 found clinicians are not very accurate in diagnosing imminent death and “there are no precise ways of telling accurately when a patient is in the last days of life.”²⁹

A 2016 study of palliative care in Scotland indicated only 40% of non-cancer patients are formally identified as being near the end of life at the time of their death.³⁰

Though there are a wide range of terminal conditions, 26,400 of the 30,300 people claiming PIP under the special rules had a ‘neoplasm’ (a catch-all term used for abnormal growths such as cancer) in October 2021.³¹

The unpredictability of many terminal conditions can place doctors and other medical professionals who are expected to determine whether a person is terminally ill under the definition in difficult positions. In submissions to the All-Party Parliamentary Group (APPG) for Terminal Illness, medical professionals suggested doctors struggle to make a reliable prognosis for a wide range of non-cancer conditions.³²

²⁷ MND Association, [Letter to \[Secretary of State\] Therese Coffey](#), 28 October 2019

²⁸ An approach to care for dying patients used in the UK.

²⁹ Department for Health and Social Care, [More Care, Less pathway](#), Independent Review of the Liverpool Care Pathway, 15 July 2013, p19

³⁰ Tapsfield J, Hall C, Lunan C, et al, [Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners](#), BMJ Supportive & Palliative Care, April 2016

³¹ DWP Stat-Xplore

³² Submissions to the [APPG for Terminal Illness \(PDF\)](#) from the Royal Colleges of Nursing, Physicians and General Practitioners, July 2019

The Association of Palliative Care Professionals has described the relative difficulties people face obtaining DS1500s with non-cancer conditions compared to people with cancer as “discriminatory”, requiring many to claim under the normal rules:

The current system mainly works for people with some terminal cancers. Cancer has a clearly defined disease trajectory and it is easier to predict when someone is in the last six months of life, giving clinicians confidence to sign off the DS1500. However, six months has no clinical meaning in most terminal illnesses, because there is no clearly defined disease trajectory. As a result, many terminally ill people, including those with Motor Neuron Disease, heart failure and Chronic Obstructive Pulmonary Disease fail to access benefits under special rules, meaning they must wait much longer for their benefits and have to travel to go through face to face assessments. This position is discriminatory and, in our view, lacks humanity.³³

Marie Curie, in their “scrap six months”³⁴ campaign, argued too many people miss out on support and are “forced further into financial difficulties while they wait for benefits”:

Too often and for too long, the benefits system that should provide the support families need has failed to come to the aid of many terminally ill people when they need it the most. While terminally ill people are entitled to fast track access to many benefits without going through the normal, onerous assessment process, the law currently only recognises a dying person as eligible for this access if they have fewer than six months to live.

This rule has no clinical relevance and is opposed by most doctors, nurses and charities working with terminally ill people. It means too many people miss out on the support they need and are forced further into financial difficulties while they wait for benefits.³⁵

2.3

How many people claim under the Special Rules?

Around 70,000 people in Great Britain are entitled to extra-costs benefits under the Special Rules in Great Britain in the latest months for which data is available. The DWP’s Impact Assessment estimated that 63,390 people are entitled to extra-costs benefits under the Special Rules in England and Wales.³⁶

The chart below shows that 37,220 people were entitled to Attendance Allowance under the Special Rules in April 2022. 30,361 were entitled to

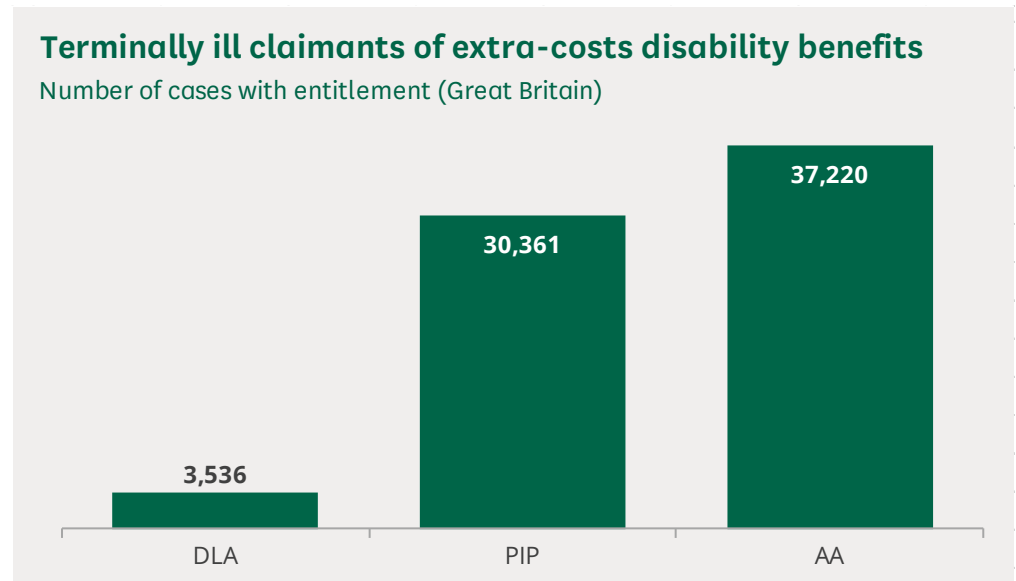
³³ Association of Palliative Care Social Workers, [Submission to the APPG for Terminal Illness](#) (PDF), July 2019

³⁴ [Marie Curie website](#) (Accessed 4 February 2022)

³⁵ [The Cost of Dying](#), Marie Curie, 3 December 2019

³⁶ DWP, [The Social Security \(Special Rules for End of Life\) Bill: Impact Assessment to extend the end-of-life definition to 12 months](#), May 2022

Personal Independence Payment, and 3,536 were entitled to Disability Living Allowance.

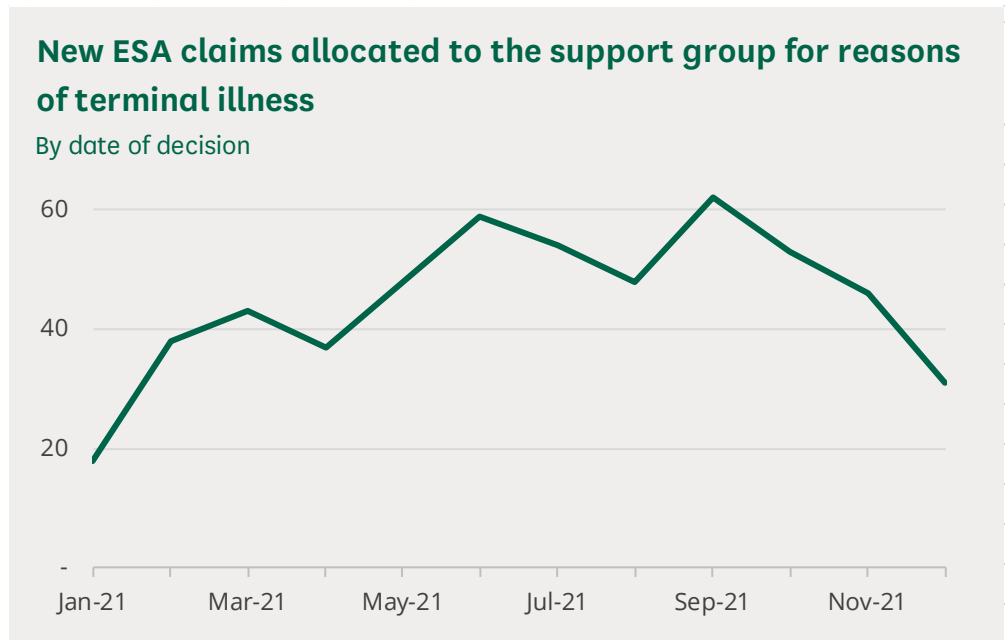


Note: As at April 2022 for PIP, and November 2021 for DLA and AA (the latest data available).

Source: [DWP Stat-Xplore](#)

The DWP does not publish caseload figures for fast-tracked income-replacement benefit claims, but does produce figures on the numbers of claimants allocated to the Employment and Support Allowance Support Group as a result of terminal illness each month. During the twelve months to December 2021, 537 claimants of ESA were allocated to the Support Group because of terminal illness.

The chart below shows the number of new ESA claims allocated to the support group (the highest level of award) for reasons of terminal illness each month in 2021. The average was 45 a month, but was higher in the summer than the winter.



Source: [DWP Stat-Xplore](#)

The DWP does not publish statistics on how many terminally ill people are entitled to Universal Credit, how many fast-tracked applications are made, or who report terminal illness, and has no current plan to do so.³⁷

³⁷ See [letter from the Work and Pensions Secretary to the Chair of the Work and Pensions Committee \(PDF\)](#), 15 July 2022, Q7

3

The 2019-21 “evaluation” of terminal illness rules

The decision to change from a six-month to a twelve-month definition of terminal illness has its roots in an “evaluation” of the existing rules announced on 11 July 2019. The then Secretary of State for Work and Pensions, Amber Rudd asked her Department to set up an “honest and in depth evaluation of how the benefits system supports people nearing the end of their life and those with severe conditions.”³⁸

A DWP press release noted that not all doctors understood the system or felt confident their diagnosis for their patients was correct, and the rules were often seen as “favouring those living with cancer” when other illnesses can also limit life. For people living with the most severe or progressive conditions, benefit processes had recently been made simpler, reducing “unnecessary reassessments.” However, the Secretary of State wanted “to look again to make sure these processes are working effectively and to see if more can be done to improve engagement with the department for claimants living with the most severe conditions.” Amber Rudd ordered her Department to seek the views of a wide range of people, including patients, doctors and nurses.³⁹

The evaluation included three strands of research:

- hearing directly from claimants, clinicians and charities about their first-hand experiences;
- considering international evidence to find out what works in other nations and the support they provide; and
- reviewing current Departmental performance to better understand how the Special Rules for Terminal Illness and severe conditions processes operate and perform.⁴⁰

On 8 July 2021 the DWP published a press release announcing the “current special rules for Terminal Illness which fast-track benefit applications for those with a terminal diagnosis of six months is to be replaced with a new twelve-month end of life definition.”⁴¹

³⁸ DWP, [Terminally ill benefit claimants deserve a fresh and honest evaluation of the way the system supports them](#), 11 July 2019

³⁹ As above

⁴⁰ [PQ73746 \[on Universal Credit: Terminal Illnesses\], 20 July 2020](#)

⁴¹ DWP, [Fast-tracked access to benefits for people with terminal illness expanded](#), 8 July 2021; see also [HCWS166, 8 July 2021](#)

The decision to adopt a 12-month rule was welcomed by chief executives of the MND Association and Marie Curie. Quoted in the DWP press release, both urged the Government to implement changes as quickly as possible.⁴²

Findings from the evaluation of the Special Rules for Terminal Illness process were published alongside a Health and Disability Green Paper on 20 July 2021. This outlined evidence that the six-month rule “is not fit for purpose” and makes it difficult for people with fluctuating conditions.

There was less consensus among respondents to the evaluation about what the six-month rule should be replaced with. The two most favoured approaches were:

- a 12-month rule, mirroring the “end of life” approach used by NHS England (with similar definitions used elsewhere in Great Britain)
- a clinical recommendation supported by guidance, without an explicit time frame⁴³

The 12-month approach was favoured by 38% of respondents, compared to 34% for the open-ended approach, which would have been similar to the rules used for Scottish Disability Assistance benefits (see below).

The Government justified the adoption of the 12-month rule arguing there are significant benefits to aligning with practice already used in the NHS. This includes:

- Minimising difficult conversations between clinicians and patients since the timing aligns with an existing process.
- Providing opportunities to take advantage of existing NHS initiatives to identify people in their final year of life.
- Helping clinicians and people near the end of life to understand and access the Special Rules.
- Avoiding conflicting messages from the health and welfare systems.⁴⁴

Respondents did note that the twelve-month rule would retain some problems associated with the existing six-month rule.

Those who supported an open-ended definition closer to the model adopted for Scottish extra-costs disability benefits said it would “give access to people with health conditions who currently find it difficult to claim under the Special Rules, particularly those with an uncertain prognosis.” However, others

⁴² As above

⁴³ DWP, [Findings from the evaluation of the special rules for Terminal Illness process](#), 20 July 2021, para 16

⁴⁴ As above, paras 14-21

worried it would “make it difficult for clinicians to make decisions about who is eligible.”⁴⁵

⁴⁵ DWP, [Findings from the evaluation of the special rules for Terminal Illness process](#), 20 July 2021, para 19

4 Changes already made across the UK

4.1 Changes to Universal Credit and Employment and Support Allowance

Universal Credit and Employment and Support Allowance are both reserved benefits in Great Britain, administered by the DWP across England, Wales and Scotland. They are administered by the Department for Communities in Northern Ireland.⁴⁶

Unlike with extra-costs disability benefits, the definition of terminal illness set out in secondary, rather than primary, legislation:

- [Regulation 2 of The Employment and Support Allowance Regulations 2008](#), SI 2008/794
- [Regulation 2 of The Universal Credit Regulations 2013](#), SI 2013/376
- [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

These were amended by [The Universal Credit and Employment and Support Allowance \(Terminal Illness\) \(Amendment\) Regulations 2022](#), SI 2022/260 to reflect the new twelve month policy. Changes came into force from 4 April 2022, meaning there are temporarily two Special Rules regimes:

- The “Special Rules for Terminal Illness” for the purposes of extra-costs benefits (DLA, PIP and AA), which continue the old six-month rule.
- The “Special Rules for End of Life”, which apply to people who have twelve months or less to live and are claiming ESA or Universal Credit.

The Special Rules for End of Life include a new medical evidence form, the [SR1](#), replacing the existing DS1500. When the Bill is enacted, the DS1500 will be phased out altogether.

⁴⁶ See Commons Library Briefing CBP-9048, [Social security powers in the UK](#)

Interim arrangements

Until the Bill is enacted, there are two different forms a medical professional may have to complete if a person is nearing the end of their life and need fast-tracked access to benefits:

- Where patients have an expected prognosis of six months or less, medical professionals should complete a DS1500. This will allow claimants to access both extra-costs benefits and income replacement benefits.
- Where patients have an expected prognosis of twelve months or less, medical professionals should complete the SR1 form. Until the Bill is enacted, this will only allow Special Rules claims for Universal Credit and ESA.

The DWP has provided guidance for both claimants and medical professionals:

- Claimants: [Get benefits if you're nearing the end of life](#) (accessed 29 June 2022)
- Medical Professionals: [The 'Special Rules': how the benefit system supports people nearing the end of life](#), updated 5 August 2022

4.2

Changes in the rest of the UK

Northern Ireland

Most social security powers are devolved formally to Northern Ireland, including all benefit accessible through the Special Rules. By long-standing convention, however – and more recently, under [section 87 of the Northern Ireland Act 1998](#) – Northern Ireland maintains ‘parity’ with social security, child maintenance, and pensions systems in Great Britain.⁴⁷

As a result, alongside changes made by the UK Government, the Northern Ireland Assembly is also adopting a 12-month terminal illness rule. The Department for Communities has said changes will come into operation from April 2022.

On 6 October 2020, before the UK Government’s position was announced, the Northern Ireland Assembly agreed a motion calling on the Minister for Communities to “bring forward immediately legislation to remove the six-month rule, provide guidance to health professionals and adopt a fairer definition of terminal illness.”⁴⁸ A 30 June 2021 written statement from Dierdre

⁴⁷ See Commons Library briefing CBP-9048, [Social security powers in the UK](#)

⁴⁸ [Northern Ireland Assembly, 6 October 2020](#)

Hargrey, the Minister for Communities, confirmed the terminal illness definition would be extended from six to twelve months.⁴⁹

The [Social Security \(Terminal Illness\) Act \(Northern Ireland\) 2022](#) received Royal Assent on 30 March 2022. Unlike in the UK, the Act amended both primary and secondary legislation across both extra-costs and income replacement benefits at the same time, allowing the Special Rules to be changed simultaneously across all applicable benefits from April 2022.

This means that in Northern Ireland, the new SR1 form allows Special Rules claims for both income replacement benefits and extra-costs disability benefits.

For further information on how claims are made in Northern Ireland see [benefits if you are living with a terminal illness](#) on the NI direct website (accessed 29 June 2022).

Annex 1 of the UK Government's [Findings from the evaluation of the Special Rules for Terminal Illness process](#) provides further background on decisions made by devolved administrations.

Scotland

The Scottish Government is introducing three new extra-cost disability benefits to replace Disability Living Allowance, Personal Independence Payment, and Attendance Allowance. These are:

- [Child Disability Payment](#) – which replaced DLA for children for all new claimants in Scotland from 22 November 2021.
- [Adult Disability Payment](#) – which is replacing Personal Independence Payment and Disability Living Allowance for all new working-age claimants in Scotland from 29 August 2022.⁵⁰
- [Pension Age Disability Payment](#) – which will replace Attendance Allowance in Scotland “in the future”.⁵¹

The new benefits use a new, open-ended, definition of terminal illness, along with guidance to support clinicians to interpret and apply the new rules.

In 2018, during the passage through the Scottish Parliament of the Social Security (Scotland) Bill (SP Bill 18) – which created the legislative framework for the Scottish social security system – an amendment was agreed providing that, for disability benefits, a person would be deemed ‘terminally ill’ if they suffered from a progressive disease and as a consequence their death could reasonably be expected within two years (rather than six months). The amendment, backed by MND Scotland and Marie Curie, was tabled by the

⁴⁹ [Changing the special rules for Terminal Illness \(SRTI\)](#), Department for Communities, 30 June 2021

⁵⁰ See Scottish Government, [Rollout of Adult Disability Payment](#), 20 June 2022

⁵¹ Scottish Government, [Evaluating the devolution of disability benefits](#), 1 October 2021, p2

Conservative MSP Jeremy Balfour, and had the support of Labour and Green MSPs.

The Scottish Government indicated it intended to overturn the amendment, citing (in addition to the cost implications) advice from medical professionals that it was clinically not possible to predict death two years in advance of it occurring. Ministers had also however received medical advice that some people not likely to die within six months would still have significant support needs, and therefore proposed further changes to the rules to include additional circumstances in which someone could be eligible for assistance under the terminal illness rules.⁵²

Two days later, however, the then Minister for Social Security, Jeane Freeman, announced a change in the Scottish Government's position.⁵³ The Minister noted while the medical professional organisations, Scotland's Chief Medical Officer and its Chief Nursing Officer had made it clear two years was too long, "...the UK Government's current 6 month limit excludes some people who should receive the support from social security that they need." She went on:

As a result I want to focus on the importance of clinical judgement and move away from only having a time limit – because any definition that only has a time limit will always exclude some people who need our support. Having continued to listen, I will now act to remove any time limit from the legislation on social security and let clinicians do the job only they can do, focusing as they will on the individual patient they have in front of them.

This will allow clinicians provide a diagnosis in a way that will minimise any unintended consequences, while enabling those who need social security support to access the maximum award that they are entitled to – quickly and with no assessment process.⁵⁴

The Scottish Government included a provision in the Social Security (Scotland) Act 2018 to introduce a new definition of terminal illness. The Act provides that, for the purposes of accessing Disability Assistance in Scotland (the replacements for DLA, PIP and Attendance Allowance), a person is to be regarded as having a terminal illness if:

...having had regard to the (Chief Medical Officer's (CMO) guidance), it is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death.⁵⁵

A new [benefits assessment under special rules in Scotland \(BASRis\) form](#) is replacing the DS1500.

⁵² [Letter from Jeane Freeman MSP, Minister for Social Security, to the Convenor of the Scottish Parliament Social Security Committee](#) (PDF), 18 April 2018

⁵³ See Scottish Government, [No time limit for terminally ill people](#), 20 April 2018. A more detailed statement was issued by Ms Freeman in a blog, [Social Security System: Terminal Illness](#), 23 April 2020

⁵⁴ As above.

⁵⁵ Schedule 5, Section 1(2) of [The Social Security \(Scotland\) Act 2018](#)

Further background on the changes in Scotland can be found in section 7.1 of the Commons Library briefing on [Accessing benefits with terminal illness](#).

5

The Bill

The [Social Security \(Special Rules for End of Life\) Bill \[HL\] 2022-23](#) completes the introduction of the new Special Rules for End of Life, ensuring the new twelve-month definition of terminal illness applies to extra-costs disability benefits.⁵⁶

The Bill is simple, comprising only two clauses.

Available on the [Bill page](#), the DWP published Explanatory Notes providing policy background and explanation of the clauses, as well as a Delegated Powers Memorandum identifying the provisions of the Bill allowing Ministers to make delegated legislation.

Clause 1, subsections (1) and (2) amend the current six-month definition in the relevant Primary legislation for Attendance Allowance, Personal Independence Payment and Disability Living Allowance by substituting “6” with “12”. The relevant primary legislation is:

- AA and DLA – [Section 66\(2\)\(a\) of the Social Security Contributions and Benefits Act 1992](#)
- PIP – [Section 82\(4\) of the Welfare Reform Act 2012](#)

Subsection (3) amends the definition of terminal illness in secondary legislation: [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](#).

Clause 2 covers, among other things, the Bill's geographical extent, and commencement of the provisions. Subsection (1) provides that the Bill extends to England, Wales and Scotland.⁵⁷

- Subsection (2) provides for the revised definition to come into effect on a date to be specified by the Secretary of State in regulations. This is to allow time for the appropriate processes to be in place within DWP to align with the change in the law.⁵⁸

⁵⁶ The twelve-month definition is already in use for income replacement benefits such as Universal Credit - see section 4.1

⁵⁷ Over time, the new Scottish extra-costs benefits will replace the benefits currently in place across Great Britain, and the provisions will only apply in practice in England and Wales.

⁵⁸ [Social Security \(Special Rules for End of Life\) Bill: Delegated Powers Memorandum \(PDF\)](#), para 13

6 Commentary on the Bill

6.1 DWP documents

The Bill completes changes to end of life rules in the benefits system first announced following the [2019-21 evaluation](#) explored in section 3 above.

Alongside the Bill the DWP published Explanatory Notes (EN) and an Impact Assessment (IA), [available on the Bill page on the Parliament website](#). The Explanatory Notes set out the policy and legal background, as well as commentary on the provisions of the Bill. The Impact Assessment provides estimates of the impact and cost of the Bill.

Estimated impact and cost of the Bill

The Impact Assessment estimates that an additional 30,000 to 60,000 Special Rules awards of extra-costs benefits will be made each year in England and Wales⁵⁹ as a result of extending the definition of terminal illness to twelve months. The central scenario is that 40,000 additional Special Rules claims will be made for AA, PIP and DLA each year.

Impact of the Bill: estimated increase in extra-costs benefits claims England and Wales	
Benefit	Awards per year
AA	23,000
PIP & DLA (working age)	14,000
PIP & DLA (State Pension age)	2,000
DLA (child)	<1,000
Total	40,000

Note: Figures rounded to the nearest 1,000.

Source: DWP, [The Social Security \(Special Rules for End of Life\) Bill: Impact Assessment](#), May 2022

Around 5,000 additional Special Rules claims for ESA and UC are estimated to be made per year under the new rules across Great Britain.

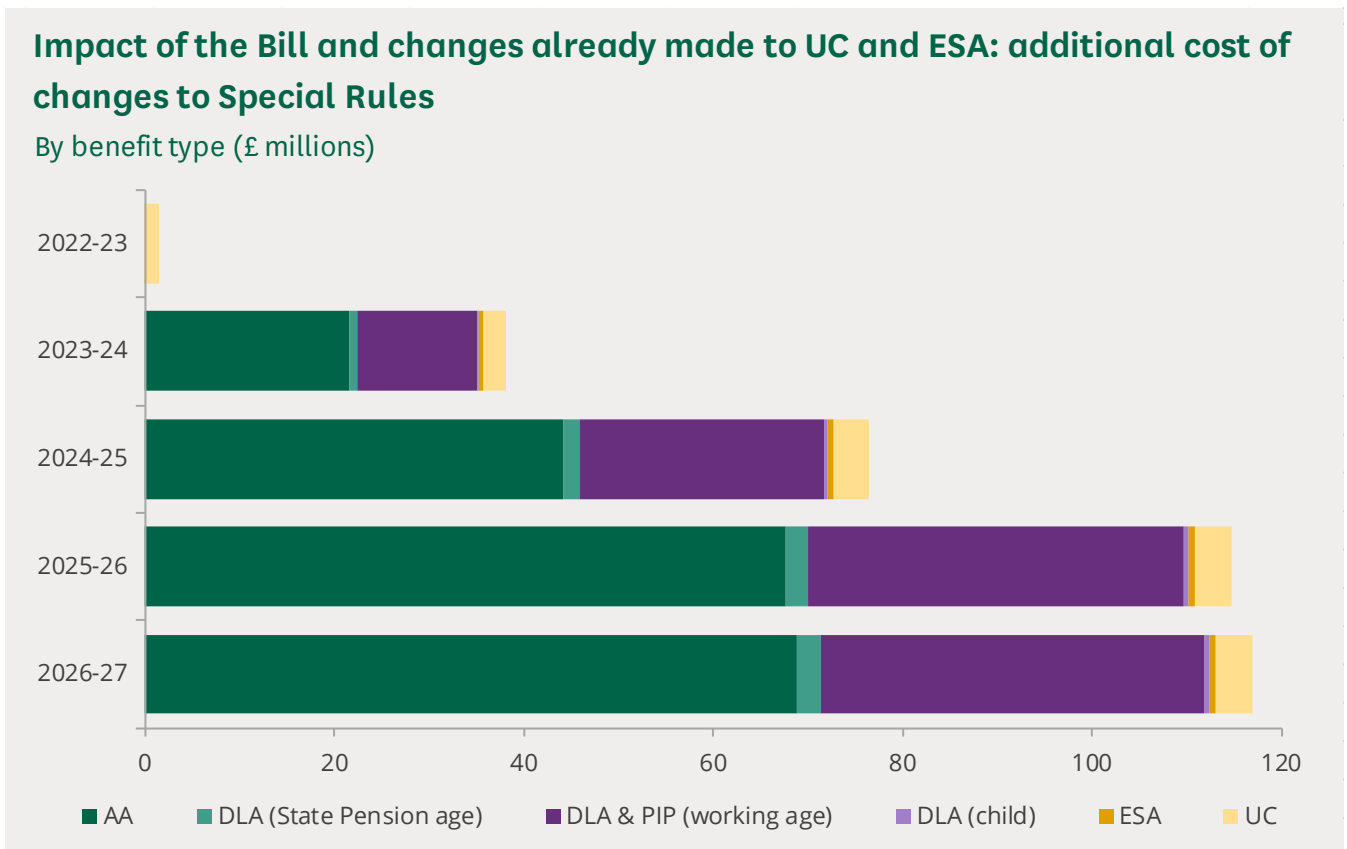
⁵⁹ Analysis of extra-costs benefits excludes Scotland; assumptions behind this range are explained in table 6 of the IA

Impact of the Bill: estimated increase in ESA and UC claims Great Britain	
Benefit	Awards per year
ESA	1,000
Universal Credit	4,000
Total	5,000

Note: Figures rounded to the nearest 1,000.

Source: DWP, [The Social Security \(Special Rules for End of Life\) Bill: Impact Assessment](#), May 2022

The additional extra-costs benefit caseload created by the Bill is estimated to cost an additional £112.4 million a year by 2026-27. This is in addition to an extra £4.6 million for income-replacement benefits in 2026-27. Costs are predicted to be £38.1 million in 2023-24,⁶⁰ the first year the new rules are expected to be used for extra-costs benefits, growing in each subsequent year.



Note: Figures for AA, DLA and PIP are for England and Wales only. Figures for ESA and UC are for Great Britain.

Source: DWP, [The Social Security \(Special Rules for End of Life\) Bill: Impact Assessment](#), May 2022

⁶⁰ Across both extra-costs and income-replacement benefits.

Beyond the financial costs and expanded caseloads, the IA also notes “non-monetised benefits” include improving the quality of life for those with terminal illnesses, as financial support can be accessed earlier, adding:

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.⁶¹

6.2

Debate in the Lords

[The Social Security \(Special Rules for End of Life\) Bill \[HL\] 2022-23](#) was introduced in the House of Lords and its Second Reading was on 24 May 2022.⁶²

Second Reading

At Second Reading, Baroness Steadman-Scott, the DWP Minister in the Lords, provided background on the evaluation of terminal illness rules published in July 2021. She said the proposal to change the six-month definition to a twelve-month definition of terminal illness for the Special Rules was widely supported and fitted better with NHS practice.⁶³

All those participating in the debate, including Labour, Liberal Democrat and crossbench members, as well as Bishops, welcomed the change to the terminal illness definition in the Bill.

Some raised questions about the operation of the proposed new rules. The Liberal Democrat Member, Baroness Brinton, asked how changes would be communicated with medical professions, and raised concern that the extended definition could slow DWP decision making. The Minister noted the average time for processing Special Rules claims is three days, and that there had been “extensive communication” with medical professionals.⁶⁴

Baroness Brinton also raised the issue of the exclusion of children under the age of three from the DLA mobility component,⁶⁵ meaning terminally ill babies and their families cannot receive financial support for mobility needs. The Minister said the Department “has been in discussions with the charities Motability and Family Fund to explore options for helping this group of

⁶¹ DWP, [The Social Security \(Special Rules for End of Life\) Bill: Impact Assessment to extend the end-of-life definition to 12 months](#) (PDF), May 2022, p1

⁶² [HL Deb 24 May 2022 cc772-790](#)

⁶³ [HL Deb 24 May 2022 c772-774](#)

⁶⁴ [HL Deb 24 May 2022 c787](#)

⁶⁵ The higher rate DLA mobility component is only payable for children aged three and over, and the lower rate mobility component is payable from the age of five. There is no lower age limit for the care component of DLA. See Commons Library briefing CBP-7977, [Disability Living Allowance mobility component for younger children](#)

children”,⁶⁶ and subsequently followed up on the issue in a [30 June letter to Members of the House](#) (PDF).

The Bishop of Carlisle noted a statement by Justin Tomlinson, the former Minister for Disabled People, Work and Health that the longer a prognosis, the less likely it is to be accurate. He worried this could make conversations between doctors and patients more difficult, rather than easier. Baroness Steadman Scott recognised that prognosis is not an exact science, but gave assurances that evidence shows “the 12-month approach helps clinicians feel more confident when determining whether someone meets the special rules”.⁶⁷

The Bishop also expressed the hope that financial assistance for people nearing the end of life does not come at the expense of wider palliative care. The Minister explained the twelve-month definition had been chosen to align with existing end of life practice and might therefore allow financial support to form “part of clinicians’ holistic approach to considering their patients’ needs when they enter the final year of life”.⁶⁸

The Conservative Member Baroness Noakes expressed hope that the DWP will monitor the impact of changes and stand ready to make further changes if necessary. The Minister followed this up in the 30 June letter to Members (see below).⁶⁹

Baroness Finlay of Llandaff (Crossbench) asked about provision for those who significantly outlive their prognosis and are coming to the end of their three-year award, and well as those who do not yet have a twelve-month prognosis. The Minister responded:

A letter is sent ahead of the end of the award inviting them to resubmit information. If they continue to meet the special rules criteria, they will receive another three-year award.⁷⁰

The Conservative Member Lorde Balfe asked whether a clause could be added to the Bill allowing Ministers to amend the definition through secondary legislation. The Minister replied: “There are no plans to change the law again”.⁷¹

Baroness Janke (Liberal Democrat) asked whether the Government would consider recommendations made by the APPG for Terminal illness: that fast-tracking be allowed from the point a terminal illness is diagnosed, and Special Rules claims should only be reassessed with a “light-touch” approach after 10 years.

⁶⁶ [HL Deb 24 May 2022 c786](#)

⁶⁷ [As above](#)

⁶⁸ [HL Deb 24 May 2022 cc786-787](#)

⁶⁹ [Letter from Baroness Steadman-Scott to Members regarding issues raised in the second reading debate](#) (PDF), 30 May 2022

⁷⁰ [HL Deb 24 May 2022 c787](#)

⁷¹ [HL Den 24 May 2022 c788](#)

The Bill received a Second Reading without a vote. No amendments were tabled for the Lords Committee Stage, so proceedings on the Bill continued with Third Reading on 22 June 2022.⁷²

Letter to Members following Second Reading

Following Second Reading, Baroness Stedman-Scott wrote to Members to follow up on issues raised at the Second Reading debate:

On the issue of how the DWP will monitor the impact of changes. The Minister promised:

- To continue to engage with stakeholders to ensure that those who meet the definition are able to claim.
- To monitor existing claimant feedback channels.
- For claimants who do not meeting the new definition, the DWP is testing an approach for “a new Severe Disability Group,⁷³ so that those people can benefit from a simplified process that does not involve a face-to-face assessment.”

Referring to the Social Security Advisory Committee report and review of eligibility criteria for PIP/DLA mobility component for children aged under three, the Minister shared part of the Government’s response to the SSAC report, noting:

Only children over the age of three can claim the mobility component of DLA, as all younger children have substantial mobility needs. The Department has however recognised the difficulties faced by families with severely disabled children under three, and so explored options for helping these children with the Motability and Family Fund charities. A first phase 18-month pilot scheme was launched, in January 2018. Those eligible benefitted from a fully funded leased vehicle via Motability Operations, and the scheme was funded by Motability. Motability have extended the successful pilot to the end of July 2021 while considering next steps.

In the letter the Minister also included data on the proportion of Special Rules claimants living longer than six months.⁷⁴

Third Reading

At Third Reading, Labour’s Baroness Sherlock explained she had not tabled amendments in order to not to slow the legislative process:

We chose not to table amendments to the Bill, even though I would have liked the opportunity to explore some of the issues about the support available to

⁷² [HL Deb 22 June 2022 cc236-239](#)

⁷³ See DWP, [Shaping future support: the health and disability green paper](#), CP 470, updated 12 August 2021, chapter 3

⁷⁴ [Letter from Baroness Stedman-Scott to Peers regarding issues raised in the second reading debate](#) (PDF), 30 May 2022

people nearing the end of their life. However, it is really important to get this onto the statute book as soon as possible because, at the moment, some benefits are available only to those with six months to live and others are for those with 12. That is confusing for clinicians and patients, so we want to support this getting there as fast as possible. I hope that the Minister can assure the House that the Government will reward our restraint by ensuring that the Bill gets through the other place before the Summer Recess.⁷⁵

Noting the Scottish Government had taken a different, open-ended approach to defining terminal illness for benefits purposes, Baroness Sherlock asked the Minister to assure the House the Government would evaluate the effectiveness of its chosen approach, and compare it with that taken in Scotland.

Replying to Baroness Sherlock, and to similar points made by the Liberal Democrats' Baroness Brinton, Baroness Stedman-Scott confirmed the Government would "continue to monitor our own approach and watch with interest the different approach taken by the Scottish Government as it is fully rolled out".⁷⁶

⁷⁵ [HL Deb 22 June 2022 c237](#)

⁷⁶ As above

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