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Accessing benefits with terminal illness



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Summary

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

There is no benefit specifically designed to help people who are terminally ill cope with these financial impacts. However, there are rules in place which allow simpler and faster access to certain benefits:

- Benefits designed to help with the additional costs of disability and ill health - Disability Living Allowance, Personal Independence Payment, and Attendance Allowance.
- Income replacement benefits for people whose ability to work is affected by disability or ill health – Employment and Support Allowance and Universal Credit.

The Special Rules are necessary because the normal process of claiming benefits takes time and can impose burdens unsuitable for those who may be in the closing months of their lives. Some benefits also have qualifying periods where claimants must usually have conditions for months before entitlement begins. The period between applying, undergoing assessments and entitlement being determined can also take months.

‘Terminal illness’ for Department for Work and Pension (DWP) purposes has been defined in legislation since 1990. A person is regarded as terminally ill if they have a ‘progressive disease’ and as a result their death ‘can reasonably be expected within six months.’ Claimants who meet the definition of terminal illness, or those claiming on their behalf, are advised to get a medical professional to complete a ‘DS1500’ form confirming that they meet the six-month criteria.

In recent years, this definition has come under criticism for being too narrow, making it difficult for some terminally ill people to access benefits. Critics of current policy have also pointed to problems faced by people who live for more than three years after awards are made under the SRTI, whose situation is often reviewed.

In response, governments which have power over benefits systems across the UK have announced a series of changes, including scrapping the six-month rule:

- The Scottish Government announced in 2018 that it would scrap the six-month requirement for benefits it has power over, replacing it with a

broader, non-time-limited definition. This has been used since July 2021 when Scotland's new extra-costs disability benefits began to be rolled out.

- The UK Government announced in July 2021 that it would be replacing the six-month criteria with a twelve-month end of life approach.
- The Northern Ireland Executive also announced in June 2021 that it would adopt a twelve-month approach.

This Commons Library Briefing Paper explores the history of these rules, how they work in practice, the debate that surrounds them, and recent policy developments across the UK.

1 Introduction

In its report '[The Cost of Dying](#)', Marie Curie ¹ notes that individuals and families can experience significant financial impact as a result of terminal illness.

Additional costs of care and mobility, which can often escalate as disease progresses, result from many terminal conditions. These costs can include personal care, equipment and home adaptations, as well as often overlooked expenses like travelling for treatment and changing dietary requirements.

Being diagnosed as terminally ill can also have an immediate effect on a person's ability to work and support themselves financially. Families, on whom the responsibility to provide care often falls, can also face **income loss** due to the impact of terminal illness. ²

In the United Kingdom there are benefits for people with disabilities and long-term health conditions designed to address both these problems:

- Categorical benefits, which help people with the additional costs of disabilities and long-term health conditions. These include [Disability Living Allowance](#) (DLA), [Personal Independence Payment](#) (PIP), and [Attendance Allowance](#) (AA), which provide financial support for the extra care and mobility needs of, respectively, children, working age people, and pension age adults, regardless of their household's wider financial situation.
- Income replacement benefits, which provide support to people whose ability to work is affected by a disability or long-term health condition. These include [New Style Employment and Support Allowance](#) (ESA), which people can claim if they have made sufficient National Insurance contributions, and [Universal Credit](#) (UC), which is means tested.

The main issue for people with terminal illnesses is that the normal processes for accessing these benefits can be burdensome and time consuming. For instance, median end-to-end clearances ³ for Work Capability Assessments ⁴ took 107 days in September 2020. ⁵ Some of these benefits also have

¹ A charitable organisation which provides care and support to people with terminal illnesses and their families.

² Marie Curie, [The Cost of Dying](#), December 2019

³ The period between registering an ESA claim and an award decision being made.

⁴ An assessment normally required to access ESA or the LCWRA element in UC.

⁵ Department for Work and Pensions, [ESA: Work Capability Assessments, Mandatory Reconsiderations and Appeals: June 2020](#), 11 June 2020

‘qualifying periods’ which require claimants to show that they have satisfied the conditions of the benefit for a period before entitlement begins.

Of the 3.6 million people who registered a claim for PIP between April 2013 and April 2018, just over 17,000 people died awaiting the outcome of a decision for Personal Independence Payment, though not all of these deaths will have been due to a terminal illness.⁶

In order to prevent people from missing out or having to go through these processes in what may be the final months of their lives, there are “Special Rules for Terminal Illness” (SRTI)⁷ allowing simpler and faster access to these benefits.

⁶ [PQ 203812 \[on deaths before PIP assessment completion\] 11 January 2019](#)

⁷ This briefing uses SRTI as a shorthand, but Universal Credit legislation and guidance does not use the term. However, the same principle of fast-tracking is applied in UC to terminally ill claimants.

2

The definition of terminal illness

Policies announced by the Scottish Government in 2018 (see section 7) and UK Government in July 2021 (see section 8) will replace the existing definition of terminal illness across Great Britain. However, at the time of publication, in order to apply under the Special Rules a claimant, or someone claiming on their behalf, must show that they meet a definition of terminal illness which dates to 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

This legislation also established the preferred 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. The form is not itself a claim form for any benefit, but provides evidence enabling the DWP to make awards under the Special Rules.

When a person is diagnosed as terminally ill, their prognosis in terms of months of remaining life may not be clear. The definition has been criticised as being too narrow and ambiguous, and may be interpreted differently by doctors, making it difficult for some terminally ill people to obtain DS1500s.

Following consultation, the Scottish Government is to remove the six-month requirement⁹ (see section 7). Following an evaluation, the UK Government announced in July 2021 that it would be replacing the six-month rule with a twelve-month definition (see section 8 below).

In advance of these changes, in Spring 2019, the DWP revised guidance notes following consultation with stakeholders, adding clarification on when healthcare professionals should complete the form:

‘You should complete the [DS1500] form promptly if you believe that your patient meets the special rules criteria, namely:

- they have a progressive disease and, as a consequence of that disease

⁸ Section 1 of The [Social Security Act 1990](#)

⁹ Scottish Government Social Security Directorate, [Terminal Illness and Disability Assistance: policy position paper](#), 28 February 2019

- you would not be surprised if your patient were to die within 6 months’

The special rules criteria do not just apply to patients with cancer.¹⁰

Debates on the definition and the reforms announce in recent years are discussed below.

History of the definition

Defining a person as having terminal illness when death can ‘reasonably be expected within six months’ is based on 1990 changes to social security law designed to address particular problems terminally ill people had accessing Attendance Allowance - a benefit now limited to people over State Pension Age who need help with personal care or supervision because of illness or disability, but which was then available to any qualifying person over the aged two or over.¹¹

As today, Attendance Allowance had a [qualifying period](#), requiring a claimant to show that they had 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 eligible for 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 that the qualifying period be waived.¹²

The Act created the following definition which (gender pronouns aside) is still in use at the time of writing:

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.¹³

Nicholas Scott, the then Minister of State for Social Security, stated that 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”.¹⁴

¹⁰ DWP, [Medical \(factual\) reports: A guide to completion](#), updated 26 march 2021, para 2.7.1

¹¹ See Section 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 for different additional costs disability benefits.

¹² Social Security Advisory Committee, *Benefits for Disabled People: A Strategy for Change*, November 1988

¹³ Section 1 of [The Social Security Act 1990](#)

¹⁴ SC Deb (G) 1 February 1990

Speaking in a Standing Committee in 1990, Mr Scott added that the intention was to help people who would die before the end of the qualifying period. Responding to an amendment what would have extended the definition to two years, Mr Scott said:

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.¹⁵

While this suggests that there were other considerations, the main reason why six months was chosen appears to have been removing the qualifying period. Interventions in Parliament and other parliamentary questions¹⁶ from both Government and backbench MPs calling for special arrangements referred to concerns about the six-month ‘qualifying period’ in Attendance Allowance. 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.¹⁷

A report published by the Industrial Injuries Advisory Council in 2014 commented that the definition of terminal illness employed in the Special Rules ‘was pragmatically based on a benefit waiting time, rather than scientific evidence’.¹⁸ 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:

There was a conversation this evening about the definition of terminal illness. Our definition of someone who is terminally ill is that they have a progressive disease and a life expectancy of six months or less. 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

¹⁵ Ibid

¹⁶ For example see [HC Deb 6 Feb 1989 c490](#) and [HC Deb 6 March 1989 c585](#)

¹⁷ [HC Deb 22 January 1990 c629](#)

¹⁸ Industrial Injuries Advisory Council, [Terminal Cancers and Industrial Injuries Disablement Benefit](#), April 2014, Cm 8846, para 33

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.¹⁹

However it came about, the definition was subsequently adopted for other disability benefits, creating the policy that has exists today, pending implementation of announced changes.

Disability Living Allowance (DLA) replaced Attendance Allowance for people under 65 in 1992, retaining the terminal illness definition²⁰, and was later replaced for people of working age by Personal Independence Payment (PIP)²¹. The definition was later used to allow terminally ill people to access Incapacity Benefit²², and subsequently replicated in Employment and Support Allowance²³ and Universal Credit.²⁴

The Social Security Act 1990 also established the process of applying under the Special Rules – through a form that could be used to claim Attendance Allowance (see section 3.2):

It shall be the duty of the Secretary of State to publish a draft of the first form to be used by terminally ill persons for claiming an attendance allowance, to invite comments on the draft from interested persons and organisations and to consider any such comments received within one month of that invitation before ordering the printing of the form.²⁵

¹⁹ [HC Deb 09 May 2018 cc867-8](#)

²⁰ Section 72(5) of [The Social Security Contributions and Benefits Act 1992](#)

²¹ Section 82(4) of [The Welfare Reform Act 2012](#)

²² See [HC Deb 24 January 1994 c41](#) and section 2(4) of [The Social Security \(Incapacity for Work\) Act 1994](#)

²³ Section 2 of [The Employment and Support Allowance Regulations 2008, SI 2008/794 \(as amended\)](#)

²⁴ Section 2 of [The Universal Credit Regulations 2013, SI 2013/376 \(as amended\)](#)

²⁵ Section 1(7) of [The Social Security Act 1990](#)

3 Applying for benefits under the Special Rules

If criteria are met, and the system works as intended, the Special Rules allow people to access benefits within days, rather than the weeks it often takes to go through a Personal Independence Payment assessment or Work Capability Assessment. Some types of award are made at the maximum level by default and certain requirements are waived. While groups such as The MND Association have highlighted issues accessing benefits even where a DS1500 form is obtained, the Department for Work and Pensions states, for example, that ‘nearly all (99%) SRTI claims’ (excluding withdrawn claims) receive an award of Personal Independence Payment.²⁶

3.1 Benefits accessible through Special Rules

Special Rules claims can be made for several disability benefits²⁷:

- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- Attendance Allowance (AA)
- ‘New Style’ Employment and Support Allowance (ESA)
- Universal Credit (UC)

As it is replaced by PIP for people of working age, new claims for DLA can only be made for children under 16. Income-related ESA is one of the six benefits currently being replaced by Universal Credit. As a consequence, new claims for income-related ESA are no longer possible (except in a very limited set of circumstances). As with people claiming under the normal rules, those with terminal illnesses may still apply for contributory ‘[New Style ESA](#)’.

A person who qualifies under the SRTI²⁸ will usually automatically receive the following rates of benefits:

²⁶ DWP, [Personal Independence Payment Statistics to April 2020](#), 28 July 2020

²⁷ We have not included benefits such as Severe Disablement Allowance, which are not open to new claims.

²⁸ Claimants will still have to meet eligibility criteria and certain exclusions remain such as for persons subject to immigration control.

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 over the age of 16 who have not reached pension age	Enhanced rate daily living component
Attendance Allowance (AA)	Adults over pension age	Higher rate
Employment and Support Allowance (ESA)	Adults under pension age who have a disability or health condition that affects how much they can work ²⁹	Support Group / Support Component
Universal Credit (UC)	Adults under pension age who have a disability or health condition that affects how much they can work ³⁰	Limited capability for work and work related activity (LCWRA) / LCWRA element

Terminally ill claimants also don't have to serve the usual 'qualifying period' before they can receive extra-costs disability benefit (3 months for DLA/PIP; 6 months for AA). They can also receive the UC LCWRA element or the ESA Support Component straight away. For UC claimants, there is usually a three month wait – referred to as the 'relevant period' – before the LCWRA element can be added to their award. This corresponds to the 13 week 'assessment period' for ESA – for ESA claimants found to have LCWRA, the additional Support Component is normally only be payable from the beginning of the 14th week of their claim.

In addition, they may also receive other elements (such as the housing costs element in UC) or components (such as the mobility component of PIP) of benefits which they are not automatically entitled to under the Special Rules. The process of applying for each benefit that can be accessed through the SRTI is explored below.

²⁹ Most new ESA claims will be for contributory 'New Style' ESA, which is available for people with a disability or health condition that affects how much they can work and have also paid sufficient National Insurance contributions over the last 2-3 years. Claimants who might have applied for income-related ESA, which does not depend on National Insurance contributions, but which is means-tested, will usually now apply for Universal Credit.

³⁰ In mixed age couples (one under, one over pension age) the pension age partner may be awarded the limited capability for work and work-related activity (LCWRA) element.

3.2

Getting a DS1500

In order to apply for the eligible benefits under the Special Rules, a claimant (or someone acting on their behalf) usually obtains a DS1500 form from a medical professional confirming that they meet the terminal illness criteria. This form can be filled out by a GP, consultant or certain other professionals, including Macmillan nurses. The claimant should not have to pay as the medical professional can also submit a fee form alongside the DS1500.³¹

The form is not a requirement, but it is the Department's preferred, and most commonly used, approach for applying under the special rules.

DS1500 forms have never been a requirement for a claim under the terminal illness rules but remain the quickest and most appropriate route to gather evidence to support entitlement in these cases. Where it is not possible to supply a DS1500 in support of a terminal illness claim the Department will continue to consider alternative evidence and work flexibly and quickly with the claimant and/or their clinician(s) to make a quick determination.³²

For PIP, AA and DLA, any person representing a terminally ill person can make a third party claim on their behalf, even if the person is unaware that a claim is being made.³³ In the case of UC and ESA, [consent can be given](#) for another person or organisation to help deal with a claim.³⁴

Building on the legal definition of terminal illness, the DWP's guidance tells medical professionals that they should complete the form for a patient if:

they have a progressive disease and, as a consequence of that disease

you would not be surprised if your patient were to die within 6 months³⁵

The form itself asks medical professionals for:

- information about diagnosis, relevant conditions and how they are likely to progress
- whether the patient is aware of their condition and/or prognosis
- relevant treatments and interventions which might alter the prognosis³⁶

³¹ DWP, [Personal Independence Payment Handbook](#), updated 6 December 2018

³² DWP lines shared with the House of Commons Library

³³ DWP, [Medical \(factual\) reports: A guide to completion](#), updated 26 April 2021

³⁴ DWP, [Universal Credit guidance: Terminal Illness v17.0](#), updated 26 April 2021 and GOV.UK, [Get benefits if you're terminally ill](#), accessed 12 October 2020

³⁵ DWP, [Medical \(factual\) reports: A guide to completion](#), updated 26 April 2021

³⁶ Ibid

Once completed, the medical professional can submit the form to the DWP either electronically or by post. Alternatively, the completed form can be submitted by the person making the claim or by someone acting on their behalf. In some cases, disability benefit assessment providers may contact the healthcare professional who filled out the DS1500 to clarify information, or where a Special Rules claim has been made but a DS1500 has not been submitted.

Discussion of both how easily people with terminal illnesses can access DS1500s and the DWP's processes where they have been completed are covered below.

The DS1500 form itself is not an application for any benefit. With a completed form, claims can then be made for the relevant benefits under the Special Rules. Where claimants with terminal illnesses are unable to obtain a DS1500 because a medical professional does not think that they satisfy the criteria, they may still be entitled to claim these benefits under the normal rules.

3.3 Personal Independence Payment

The DWP's PIP Handbook explains the claims process under the Special Rules.³⁷ 29,200 of the 2.71 million people claiming PIP in April 2021 were doing so under the Special Rules.³⁸

Claimants applying for PIP under the Special Rules do not have to wait the three-month qualifying period before their eligibility for PIP starts, and they automatically qualify for the enhanced rate of the daily living component.

They will not have to fill in the 'How your disability affects you' (PIP2) form or attend a face-to-face consultation that would normally be required for most claimants. Although PIP claimants (or someone claiming on their behalf) can request a hard copy claim form, the DWP's [preferred approach](#) is for people to initiate a claim by phoning the Department.

Terminally ill claimants who also need support with additional mobility costs will not automatically qualify for the mobility component, but a decision about it can usually be made more quickly using information about their condition and how it affects their ability to get around gathered by a DWP agent over the phone. If they do qualify for the mobility component, they will not have to wait the three-month qualifying period to receive it.

If an assessment provider (i.e. Atos or Capita) needs more information, they may contact the medical professional who completed the DS1500 form.³⁹

³⁷ DWP, [Personal Independence Payment Handbook](#), updated 6 December 2018

³⁸ DWP Stat-Xplore

³⁹ DWP, [Personal Independence Payment Handbook](#), updated 6 December 2018

Awards under the Special Rules for terminal illness will normally be made for three years. A reminder will be issued before the award expires to remind the claimant to re-claim PIP.⁴⁰

3.4 Disability Living Allowance and Attendance Allowance

Following in the introduction of PIP, new claims for DLA can only be made for children under the age of 16. Special Rules claims for children under 16 are made in the same way as those for Attendance Allowance. Just under 3,800 of the 1.38 million people claiming DLA in November 2020 had a terminal illness and their ‘main disabling condition’.⁴¹

Anyone over 16 who is currently claiming DLA when they receive a terminal diagnosis may be eligible for a higher rate of support under the Special Rules. In this case, they will be invited to claim PIP under the Special Rules⁴².

When filling in the [Attendance Allowance claim form](#), the claimant, or whoever is claiming on their behalf, is asked to indicate that they wish to claim under the Special Rules and submit a DS1500 alongside their application. Around 37,300 of the 1.53 million people claiming Attendance Allowance in November 2020 had a terminal illness as their ‘main disabling condition’.⁴³

Special Rules claimants do not have to serve the three-month qualifying period for DLA, or the six-month qualifying period for Attendance Allowance. They automatically qualify for the highest rate DLA care component, or the higher rate of the Attendance Allowance.⁴⁴ A child or young person under 16 meeting the terminal illness criteria does not automatically qualify for the DLA mobility component and must meet the usual conditions to be awarded it (apart from the requirement to serve the qualifying period).

Special Rules claims for AA and DLA can be awarded for fixed or indefinite periods, though the Disability Living Allowance Advisory Board have recommended that three years would normally be an appropriate fixed period.⁴⁵

⁴⁰ DWP, [Advice for decision making Chapter P2: Assessment for PIP](#), updated 9 July 2021, para 2079

⁴¹ DWP Stat-Xplore

⁴² DWP, [Personal Independence Payment Handbook](#), updated 6 December 2018

⁴³ DWP Stat-Xplore

⁴⁴ Sections 72(5) and 66 of the [Social Security Contributions and Benefits Act 1992](#)

⁴⁵ DWP, [Decision Maker's Guide, Vol 10: benefits for incapacity, disability, maternity and bereavement](#), updated 27 January, 2020, para 61504,

3.5 ‘New Style’ Employment and Support Allowance

Most new ESA claims will be for contributory ‘[New Style’ ESA](#), which is for people with a disability or health condition that affects their capability for work, and who have paid sufficient National Insurance contributions over the previous two to three years. Claimants who might have applied for income-related ESA, which is non-contributory but means-tested, will usually apply for Universal Credit. Just over 900 of the 272,500 people who completed a WCA for ESA in the year to December 2020 did so under the Special Rules.⁴⁶

Claims for New Style ESA can be fast-tracked, and Special Rules claimants are automatically determined to have limited capability for work and for work-related activity (LCWRA). This entitles them to a higher level of support in both benefits and means they will not have to meet work-related responsibilities to keep getting the benefit in full.

Under the normal rules, the ESA Support Component is usually only payable once a person has undergone a Work Capability Assessment (WCA), which normally involves attending a face-to-face assessment. The Special Rules allow people to qualify for these automatically, without undergoing a WCA.

For New Style ESA, claimants, or those applying on their behalf, must provide the information requested on the [NSESAF1 claim form](#), but if a valid DS1500 form has been submitted they should not be issued with an [ESA50 capability for work questionnaire](#) or be invited to a face-to-face assessment.

Where a claimant indicates that they are terminally ill, DWP will normally make a referral to an assessment provider (i.e. Maximus, which operates as the Health Assessment Advisory Service). A check is then undertaken to see whether a DS1500 has been submitted with the claim, or in relation with a separate claim for an extra-costs benefit. If a DS1500 has been submitted in relation to a claim for benefit and this confirms that the person meets the SRTI criteria, the assessor will inform the DWP via the standard ESA85 report. If the advice is accepted by the DWP Decision Maker, the claimant will be determined as meeting the criteria of having limited capability for work and work related activity (LCWRA), will be placed in the ESA Support Group and will receive the additional Support Component from the beginning of the claim, without having to serve the 13-week ‘assessment period.’

Most people are not paid benefit for the first seven days of their ESA claim.⁴⁷ But claimants under the Special Rules will be paid for these ‘waiting days’.

⁴⁶ DWP Stat-Xplore

⁴⁷ These rules were temporarily suspended during the coronavirus crisis. See part 4 of [Coronavirus. Support for household finances. Commons Library Briefing Paper CBP-8894. 22 June 2020](#)

After a three-year period, the DWP will review the status of any ongoing ESA claims made under the Special Rules.⁴⁸

3.6 Universal Credit

The DWP's Universal Credit Guidance chapter on Terminal illness⁴⁹ provides guidance on how existing and new UC claimants can report terminal illness. Universal Credit is a means-tested household benefit with complex [eligibility rules](#). Claimants with terminal illness have to satisfy these, but may have new claims fast-tracked and can receive increased awards.

Like the ESA Support Group, Universal Credit claimants can usually only access the limited capability for work and work related activity (LCWRA) element after undertaking a work Capability Assessment.

A new or existing UC claimant can inform the DWP that they have a terminal illness at any time, including during the new claim stage. At this stage they can request a 'call back'. The UC Guidance chapter states that before calling the claimant the staff member should check what information the claimant has entered on their online account, and whether the claimant has already provided confirmation of terminal illness to the DWP (for example, when making a claim for PIP under the Special Rules). The guidance states that during the call back staff should:

- support the claimant to make their claim (if needed)
- establish the nature of the claimant's health condition or disability
- explain why a DS1500 form is needed - see Confirming the claimant has a terminal illness
- explain the Work Capability Assessment (WCA) process to those with a prognosis over six months
- explain the next steps in the Universal Credit claim
- offer any extra help they may need – signposting to support charities
- answer any questions

The DWP should check whether a DS1500 has been received in support of other benefits such as PIP or New Style ESA. If not, the claimant or their doctor/healthcare professional will have to submit one. Once the DWP is

⁴⁸ DWP, [Work Capability Assessment Handbook](#), updated 8 October 2020

⁴⁹ DWP, [Universal Credit guidance: Terminal Illness v17.Q](#), updated 21 October 2019

satisfied that the claimant meets the terminally illness criteria with a life expectancy, they are treated as having limited capability for work and work-related activity (LCWRA).⁵⁰

For existing claims where a terminal diagnosis is reported as a change of circumstances, eligibility for the additional amount available for those with LCWRA is from the date of the diagnosis. For a new claim the LCWRA element may be awarded from the date of the claim.

Though the application process and automatic entitlements under ESA and UC are similar, the former is paid fortnightly and the latter monthly. As a result, UC claimants must wait five weeks before their first payment, even where they claim under the special rules. Advance Payments are available during this period and are generally deducted from subsequent payments for a period of up to 12 months. From October 2021, this will increase to 24 months.⁵¹

In response to a series of parliamentary questions tabled by the then Work and Pensions Committee chair Frank Field, the DWP Minister Sarah Newton said in a written answer in March 2019 that once a correctly completed form DS1500 is received, the decision that a person has LCWRA for Universal Credit is normally made “within a few days.”⁵² The Minister emphasised that under UC all claimants, including people who are terminally ill, received “continuous tailored support managed through personal work coaches, who know each person.” She also stated that claimants with a terminal illness have “several options for how they would like to progress their claim, and we will support them in the most sensitive way possible”, adding:

For example, if they would rather not continue submitting information online, our Jobcentre staff can either telephone or visit them, to provide support in making their initial claim and completing any other administrative tasks required to ensure that they receive the correct payment. If a claimant does not want to tell us about their condition themselves, then they can appoint a representative, such as a relative, friend, doctor or charitable organisation to let us know on their behalf. We accept information directly from claimant representatives, such as claimant appointees or third party organisations representing the claimant, as well as details supplied to DWP Universal Credit partnership managers or external engagement officials.⁵³

Unlike other benefits, there is no review period for terminally ill claimants of UC. The claim continues until the DWP are notified of a change of circumstances which materially impacts the terminal illness diagnosis.

⁵⁰ Claimants who receive an LCRWA element prior to reporting terminal illness will not receive any increased award.

⁵¹ HM Treasury, [Budget 2020](#), 12 March 2020, part 2.1

⁵² [PQ 227959 \[on Universal Credit: Terminal Illnesses\]](#) 7 March 2019

⁵³ Ibid

The DWP did not, at the time of writing, produce statistics on how many people claim UC, or how many applications are made, who report terminal illness.⁵⁴

⁵⁴ PQ [277207 \[on Special Rules application statistics\]](#) 15 July 2019 and [PQ 76650 20 July 2020](#)

4

Criticisms of the process of applying under the Special Rules

In recent years there have been criticisms of both the definition of terminal illness and the process of applying under the Special Rules from end of life care providers, welfare rights advisers and other campaigning groups. These complaints have fallen into three broad categories:

- Difficulties medical professionals face assessing reasonable expectation of death within six months and issuing DS1500s.
- Problems for people who do not meet the Special Rules criteria and who therefore have to apply under the normal rules.
- Problems accessing benefits even when a DS1500 has been issued.

Such concerns are not new. In May 1990, before the terminal illness rules were in statute, the campaigning group Disability Alliance⁵⁵ submitted evidence to the House of Commons Social Services Committee questioning the choice:

Whilst the waiving of the six month rule for people with terminal illness is undoubtedly welcome, what is the justification for this waiting period in other cases? The plight of people who are as disabled on day one as they will be six months later, or that of someone who is terminally ill but is expected to live for longer than six months, remains unresolved.⁵⁶

4.1

Difficulties obtaining DS1500 forms from medical professionals

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 that 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 decide whether a person can reasonably be expected to die within 6 months. For instance, Motor

⁵⁵ Now part of Disability Rights UK

⁵⁶ Social Services Committee, Community care: Planning and cooperation, 17 July 1990, HC 580, p323

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.⁵⁷

Prognostic uncertainty is not limited to MND but can apply to a wide variety of terminal conditions. A review of the Liverpool Care Pathway⁵⁸ in 2013 found that clinicians are not very accurate in diagnosing imminent death:

...diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life.⁵⁹

A 2016 study of palliative care in Scotland indicated that only 40% of non-cancer patients are formally identified as being near the end of life at the time of their death⁶⁰.

Though there are a wide range of terminal conditions, 23,000 of the 29,200 people claiming PIP under the Special Rules had a 'Neoplasm' (a catch all term used for abnormal growths such as cancer) in April 2021.⁶¹

The unpredictability of many terminal conditions can place doctors and other medical professionals who are expected to determine whether a person is terminally ill in difficult positions. In submissions to the All Party Parliamentary Group for Terminal Illness, medical professionals⁶² suggested that doctors struggle to make a reliable prognosis for a wide range of non-cancer conditions.

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

⁵⁷ MND Association, [letter to \[Secretary of State\] Theresa Coffey](#), 28 October 2019

⁵⁸ An approach to care for dying patients used in the UK.

⁵⁹ Independent Review of the Liverpool Care Pathway, [More Care, Less pathway](#), 15 July 2013, p19

⁶⁰ 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* 2019; 9: e28

⁶¹ DWP Stat-Xplore

⁶² Royal Colleges of Nursing, Physicians and General Practitioners, Submissions to the [APPG for Terminal Illness](#) from the, July 2019

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.⁶³

Marie Curie, in their “scrap six months”⁶⁴ campaign argue that:

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.⁶⁵

4.2

Problems for people unable to claim under the Special Rules

If a person with a terminal illness is unable to obtain a DS1500, their condition could still result in additional care and mobility costs and prevent them from working. In these cases, they may be eligible to apply for benefits under the normal rules.

Compared to the Special Rules, these processes are significantly more complex and often require claimants to:

- Complete forms detailing their conditions
- Attend face-to-face assessments
- Complete assessment/relevant periods at the start of claims before they are paid in full (13 weeks for New Style ESA, 3 months for the UC LCWRA element)
- Serve qualifying periods (6 months for AA, 3 months for DLA and PIP) before they become eligible

⁶³ Association of Palliative Care Social Workers, Submission to the APPG for Terminal Illness, July 2019

⁶⁴ [Marie Curie website](#) (Accessed 5 February 2020)

⁶⁵ Marie Curie, [The Cost of Dying](#), 3 December 2019

The process of applying for these benefits, in particular the Work Capability assessment (for ESA and UC) and the PIP assessment, have been criticised by campaigning organisations as inappropriate for people with terminal illnesses.

Problems faced by those with terminal illnesses applying under the normal rules are similar to those experienced by others with disabilities and long-term health conditions – the key difference being the pressures of time, deteriorating conditions and preparations for death that terminal illness can bring. Of the 3.6 million people who registered a claim for PIP between April 2013 and April 2018, just over 17,000 died awaiting the DWP’s decision on their claim.⁶⁶

Common issues include:

- The number of claimants with serious health conditions or disabilities who are placed in the wrong ESA/UC group or PIP groups, due to deficiencies with descriptors and the assessment processes.
- Difficulties faced by certain groups, such as those with mental health conditions or learning disabilities, in navigating the assessment processes.
- High success rate for appeals against WCA and PIP decisions.
- The risk of poverty and destitution as a result of incorrect decisions.
- Difficulties experienced by claimants seeking to challenge decisions they think are wrong.
- The lack of information about outcomes for individuals applying for UC and ESA following fit for work determinations.
- The impact of assessments, frequent reassessments, and poor decision making on the physical and mental health of claimants.

Further background on the WCA and PIP assessments can be found in previous House of Commons Library briefing papers and debate packs.

- [ESA and PIP reassessments](#), Commons Library Briefing Paper CBP-7820, 10 May 2019
- The [‘Impact of Changes to Disability Support’](#), Commons Debate Pack CDP-2018-0278, 18 December 2018
- [Ten years of the work capability assessment in relation to Employment Support Allowance and Universal Credit](#), Commons Debate Pack CDP-2019-0092, 18 April 2019

⁶⁶ PQ [203812](#) [on deaths before PIP assessment completion], 11 January 2019. This includes both Special Rules and normal rules claims

4.3

Problems accessing benefits even when a DS1500 has been issued

Organisations working with claimants have also pointed to problems in the process of applying under the Special Rules, even where a DS1500 has been obtained. Citizens Advice, in its response to the All-Party Parliamentary Group on Terminal Illness, pointed to the varied experiences of applying under the Special Rules. They argue that the process works well for most, and is the one of the areas of DWP practice where they ‘frequently receive positive reports from advisers.’ This was illustrated with a client case study:

A DWP decision maker was exceptionally helpful with a PIP award for a person who had been making a claim on the basis of a terminal illness before being issued a DS1500. The decision maker not only fast tracked the claim, but helped facilitate the backdating of payments since the client had been terminally ill before his claim or issuance of the DS1500. The award was backdated to 6 weeks before date of claim.

However, processes that are supposed to be triggered by the DS1500 sometimes do not work as they are intended.

One person Citizens Advice helped in the South of England was diagnosed with cancer. Her family made an application for PIP, which was denied in the weeks before she became eligible for a DS1500. Instead of fast tracking the award, this was interpreted as evidence in a mandatory reconsideration, which delayed the period of time it took to make a decision... Though she was ultimately backdated her PIP, it meant stress and uncertainty while waiting several of her remaining weeks for an award to be confirmed and a payment to be made.⁶⁷

Other organisations have complained that assessors have contacted health professionals to question DS1500 forms⁶⁸, or that there can be problems sharing the forms between different benefit systems, particularly PIP and UC. These problems can lead to delays accessing benefits. In a submission to the Work and Pensions Committee, The National Association of Welfare Rights Advisers cited a Macmillan Adviser:

I have been told by nurses before (and I get a lot of DS1500s from them), that the DWP are keen to check the DS1500s and if they don’t put on enough information then they are sometimes rejected... The difficulties that my clients who claim UC seem to have is that it can

⁶⁷ Citizens Advice, [Submission to the APPG for Terminal Illness](#), July 2019, p6

⁶⁸ This is permissible under DWP guidance (see above)

take a while for a DS1500 to filter through to UC, especially if it's been sent to PIP.⁶⁹

4.4 Reviewing awards

Awards for both extra costs benefits and income replacement benefits made under the Special Rules are often reviewed after 3 years.⁷⁰ In a briefing they provided for Jessica Morden MP in support of her Private Members Bill (see below), the Motor Neurone Disease Association noted:

It is a clear anomaly that terminally ill benefits claimants, whose condition has no prospect of improvement, are eligible for shorter awards than those who claimed through the standard process. ESA Support Group claimants with progressive conditions are entitled to the Severe Conditions Exemption, giving them a lifetime award, while higher-rate PIP claimants can qualify for an ongoing award with a light-touch review at the ten-year point. However, claimants who used the SRTI process are not eligible for either of these longer awards, and receive a maximum three-year award. This discrepancy is not only unfair but inexplicable. There is no benefit to requiring a new claim from a claimant whose condition has no prospect of improvement. It achieves nothing but causing unnecessary stress and anxiety to the individual claimant and their families. The Government should rectify this anomaly immediately by providing indefinite awards to claimants who applied via the SRTI process.⁷¹

⁶⁹ Work and Pensions Committee, [“Small change” for dying, when law needs change](#), 30 April 2019

⁷⁰ See DWP, [Personal Independence Payment Handbook](#), updated 6 December 2018 and DWP, [Work Capability Assessment Handbook](#), updated 8 October 2020, though this is not the case in UC

⁷¹ MND Association, Briefing on SRTI for Jessica Morden MP shared with the House of Commons Library, June 2020

5

The Special Rules during the coronavirus crisis

The coronavirus crisis has prompted the Department for Work and Pensions to make a number of changes to the administration of the benefits system.⁷² GP practices and other health service providers, who are responsible for DS1500 forms, have also experienced disruption during the crisis.⁷³

The Work and Pensions Committee inquiry into the DWP's response to the coronavirus outbreak was published in June 2020, and took evidence on how the Special Rules were administered in the context of these disruptions:

159. We heard from organisations who support people with terminal illnesses that there was confusion about what evidence was needed for a claim under the Special Rules. Eve Byrne, Head of Campaigns and Public Affairs at Macmillan, said that her colleagues were hearing “a lot of mixed messages” about whether the DS1500 form (or other evidence from a clinician) was necessary or if a claimant's statement could be used instead. The Motor Neurone Disease Association echoed this, telling us that:

- We remain unclear, despite contact with the Department, on whether easements around producing evidence for Special Rules claims have officially been made, and if so whether they will be making that information public.

160. We also heard that people with terminal illnesses had found it difficult to get the medical evidence they needed during the coronavirus pandemic. We heard from the Child Poverty Action Group (CPAG) about an incident in which someone with a terminal illness had “problems retrieving medical evidence”, which led to him not being treated as having limited capability for work under the special rules. This put further stress on someone diagnosed with a terminal illness. Eve Byrne of Macmillan told us that “clinical evidence is difficult to access at this time”. She also described the difficulties faced by cancer patients, who were having to balance the risks of travelling to visit their clinician to obtain the necessary evidence against their urgent need for support from the benefits

⁷² See [Coronavirus: Support for household finances](#), Commons Library Briefing Paper CBP-8894, 22 June 2020; and [Coronavirus: Withdrawing crisis social security measures](#), Commons Library Briefing Paper CBP-8973, 30 April 2021

⁷³ See [Coronavirus: health and social care key issues and sources](#), Commons Library Briefing Paper CBP-8887, 30 June 2020

system. Support organisations, including Macmillan, have called on the Government to ‘relax the rules’ during the pandemic.

161. The Minister for Disabled People, Health and Work, Justin Tomlinson MP, said that he understood that “it can be difficult at the moment for people to get the DS1500” and that the Department had therefore “taken on board a very claimant-sympathetic approach in terms of the oral evidence [provided by claimants].” He later clarified in writing that:

- DS1500s are not a requirement for a claim under the terminal illness rules but remain the quickest route to gather evidence to support these cases... Where it is not possible to supply a DS1500 in support of a terminal illness claim we will continue to consider alternative evidence and work flexibly with the claimant and/or their clinician(s) to make a quick determination.⁷⁴

The Committee commented that the benefits system should not be exacerbating the distress already experienced by people diagnosed as terminally ill and their families, nor should it be placing unreasonable burdens on medical professionals. The Committee had nevertheless heard evidence that the DWP’s guidance to terminally ill people, support organisations, and clinicians had been “unclear and confusing.”

While welcoming the Minister’s reassurance that the Department was taking a “sympathetic approach” to Special Rules claims and that there is no requirement to provide a DS1500 form, the Committee said that the message had not yet been communicated effectively. It recommended that the Department-

...publish clear guidance for claims made under the Special Rules for Terminal Illness, including the fact that a DS1500 form is not required. It should also make clear, including on its own website, what alternative forms of evidence DWP would accept.⁷⁵

The Government responded with reference to the evaluation of the rules which began in July 2019 (see section 8 below) and noted that changes had already been made to guidance.⁷⁶

⁷⁴ Work and Pensions Committee, [DWP’s response to the coronavirus outbreak](#), 22 June 2020, HC 178 2019-21, paras 159-161

⁷⁵ Ibid. paras 162-3

⁷⁶ Work and Pensions Committee, [DWP’s response to the coronavirus outbreak: Government Response to the Committee’s First Report](#), 8 September 2020, HC 732, para 23

6 Recent UK wide campaigns for change

In recent years there have been several campaigns to reform the SRTI. Though only the Scottish Government has so far adopted a new legal definition of terminal illness for benefits purposes, these efforts have successfully prompted the UK Governments and Northern Ireland Executive to announce that they will change the rules (see sections 7-9 below).

6.1 Access to Welfare (Terminal Illness Definition) Bill

On 18 July 2018 a Private Member's Bill – the [Access to Welfare \(Terminal Illness Definition\) Bill](#) – received its First Reading in the House of Commons.⁷⁷ The Bill, introduced by Madeleine Moon MP, would have amended the definition of terminal illness for benefits purposes to provide that a person is terminally ill:

...at any time if at that time it is the clinical judgement of a health care professional that the person has a progressive disease that can reasonably be expected to cause the person's death.

Speaking at First Reading, Madeleine Moon said that the current six-month rule was far too restrictive, and particularly problematic for people with unpredictable conditions such as motor neurone disease (MND). In addition, she explained that the current definition of terminal illness had been interpreted inconsistently – some doctors interpreted the definition broadly, whereas others felt that the criteria restricted their ability to support Special Rules applications. Ms Moon explained:

This Bill seeks to reflect the changes to the definition of “terminal illness” recently announced in Scotland; there has been agreement on removing the time limit of having a life expectancy of six months or less in order for someone to be considered “terminal”. Instead, the clinical judgment of a registered medical practitioner will determine whether a person is terminally ill. When there are no effective disease-mitigating treatments, and disease is progressing rapidly, death becomes inevitable. Doctors know they cannot certify with accuracy “death within six months”, and such a time statement

⁷⁷ [HC Deb 18 July 2018 cc454-6](#)

is cruel to the patient and their family, who are struggling to come to terms with the illness and with dying.

By allowing a clinical judgment to determine whether an individual has a terminal illness, we will create a much fairer and compassionate system. To support clinicians when determining a terminal diagnosis, the proposals in Scotland allow the chief medical officer, in consultation with registered medical practitioners, to set definitions in regulations. They define when an individual has a diagnosed condition that has no further treatment available and will lead to death. Both the chief medical officer and the chief nursing officer in Scotland have reviewed and fully support the amendment in Scotland as the best way to achieve timely support for those with a terminal illness.

This Bill will create parity with Scotland, generate consistency across the UK and reflect society's recognition that our benefits system should support, not challenge or interrogate, the terminally ill.⁷⁸

The Bill did not progress further.

6.2 Work and Pensions Committee recommendations

On 19 December 2018 the Work and Pensions Committee published a report, *Universal Credit: support for disabled people*.⁷⁹ The report noted that organisations giving evidence to the Committee's inquiry had flagged up a number of problems with the Special Rules including:

While it would be preferable for some claimants with degenerative illnesses such as MND to access benefits via the Special Rules, many are prevented from doing so because they were expected to live longer than six months.

Conditions such as MND can progress unpredictably. So a declaration that a person may only have six months to live might cause distress.

Those who, despite having a terminal and rapidly progressive disease, cannot obtain DS1500 must claim UC via the standard application process, and may be subject to inappropriate conditionality requirements.

⁷⁸ Ibid. cc455-6

⁷⁹ Work and Pensions Committee, [Universal Credit: support for disabled people](#), 19 December 2019, HC 1770

Witnesses suggested that adopting the definition of terminal illness in Scotland (and in Madeleine Moon's Bill) could make claiming that benefit substantially easier and less stressful for claimants with terminal illness.

Even obtaining a DS1500 did not guarantee being able to claim UC under the Special Rules – there had been cases where third parties had had difficulty submitting DS1500 on behalf of claimants because the DWP insisted on the claimant giving “explicit consent” for the third party to act on their behalf.

In this context, the requirement to give explicit consent could mean having to confront the fact they may only have six months left to live, before they are ready to do so.

For people with conditions affecting their ability to communicate indicating consent can be difficult.

The Committee concluded that the UK Government adopt the approach taken in Scotland:

We recommend the Department adopt the approach taken in the Social Security Act (Scotland) 2018 in determining who can use the SRTI. This would permit claimants to use the SRTI if:

“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”.

We also recommend the Department allow evidence for SRTI to be submitted by third parties, without the need for explicit consent.

The UK Government's response

In their response published in March 2019 (details of the more recent evaluation can be found below), the Government did not accept the main recommendation to adopt the definition of terminal illness to be used in Scotland.⁸⁰

It had however been undertaking work with clinicians and disability charities to review the wording used by DWP around terminal illness, focussing especially on the DS1500 form. The aim of this work had been to “improve the understanding of the Special Rules process and increase the confidence levels of the clinicians engaging with this process”. The Department had made clear to clinicians that providing a prognosis in these circumstances is “not an

⁸⁰ [HC 1998 2017-19, 5 March 2019, paras 52-59](#)

exact science” and their opinion should be based on the balance of probability.⁸¹

In a subsequent letter to the then DWP Minister Sarah Newton,⁸² the then Work and Pensions Committee chair Frank Field said that he was “perplexed” by the refusal to accept the Committee’s recommendation to change the definition of terminal illness, given that the Department’s response had made clear that it expects doctors to interpret the rules flexibly. He added:

We [the Committee] have heard that the Department’s current approach can cause considerable distress to people with terminal illness and their families, and places medical professionals in a very difficult position. Our proposal is a modest one, but with the potential to bring some much-needed relief from bureaucracy for people living in enormously difficult circumstances. I simply cannot understand why the Government has rejected our recommendation out of hand, nor why it continues to block the progress of Madeleine Moon’s Access to Welfare (Terminal Illness Definition) Bill.

Mr Field said that the Committee was “keen to pursue this issue further.”

On 30 April 2019, the Work and Pensions Committee published further correspondence with Ministers on the Special Rules for Terminal Illness, together with a letter to the Committee from the Vice Chair of National Association of Welfare Rights Advisers (NAWRA), Daphne Hall, giving examples of problems individuals and advisers had experienced as a result of the “uncertainty and ambiguity” of the Special Rules and associated processes.⁸³ While welcoming changes in the language of the guidance to medical professionals on issuing DS1500 forms, Mr Field said that it was “no substitute for actually changing the law that is causing so much unnecessary distress.” The Committee’s press release stated:

...the Committee’s concerns remain that DWP is working on advice and information that is years out of date. Both medical treatments and the whole system and levels of disability benefits have changed significantly since the consultation in 2010 that Government is justifying the rules on, and there have been a series of distressing recent media reports of people dying before they complete the “normal” assessment process, with its lengthy and arduous reconsideration and appeals stages. The Committee has now written again to the new Minister for Disabled People, Work and Health presenting some new case studies from NAWRA, the welfare advisors association, which describes the human cost of the uncertainty and ambiguity of the SRTIs, and the frustrating, unclear processes both dying patients and clinicians are forced to go

⁸¹ Ibid. para 55

⁸² Work and Pensions Committee, [Re: Universal Credit for claimants with terminal illness](#), 11 March 2019

⁸³ Work and Pensions Committee, [“Small change” for dying, when law needs change](#), 30 April 2019

through in the painful and uncertain last months of a human life that is ending.⁸⁴

The [NAWRA letter](#) gives a number of case studies provided by Macmillan advisers from across the UK which highlight some of the issues within the Special Rules process, and comments made by a Macmillan welfare rights advisers with extensive experience of helping terminally-ill people claim benefits. The letter states:

As the above information and the case studies at the end of this letter show, the current process for terminal illness is not operating as well as it should for a number of reasons –

- Medical professionals not fully understanding the phrase ‘death could reasonably be expected within six months’ and deciding that a DS1500 is not appropriate
- Rigidity of specifying six months which is difficult to align with current treatments which may offer the opportunity of giving a few extra months to someone with a terminal illness
- Disagreement between professionals about whether a DS1500 should be provided
- Refusal to accept DS1500s by the DWP
- Delays in the process, particularly within universal credit

NAWRA strongly believes that the government should follow the Scottish approach thereby ensuring that people in the last stages of their lives receive the benefit they need as quickly and easily as possible.⁸⁵

6.3

All-Party Parliamentary Group report

In July 2019 the All Party Parliamentary Group (APPG) for Terminal Illness published a report, [Six Months To Live?](#) The APPG’s inquiry, launched in March 2019, sought evidence from organisations, stakeholders and individuals with relevant expertise and experience using the legal definition of terminal illness. The inquiry’s terms of reference were to determine whether:

for the purpose of gaining fast-track access to benefits, the current legal definition of being terminally ill as having six months left to live fit was for purpose; and

⁸⁴ Work and Pensions Committee, [“Small change” for dying, when law needs change](#), 30 April 2019

⁸⁵ Dated 23 April 2019

whether the six-month definition helps or hinders people affected by terminal illness to receive the support that they need.

The APPG concluded that the current legal definition of terminal illness was unfit for purpose. It held that the requirement that death can be ‘reasonably expected in six months’ in order to access benefits under the Special Rules had ‘no clinical meaning and is out of step with the reality faced by people living with terminal illness in the 21st century.’ Clinicians, charities, social and palliative care workers and medical experts who gave evidence to the APPG’s inquiry agreed that the current legal definition was ‘outdated, arbitrary in nature, asks clinicians to make predictions that they cannot make with any degree of certainty, and leads to a meaningful inequality of access to benefits for terminally ill people.’

The distress, delay and financial difficulties faced by terminally ill people and their families waiting for benefits under the normal rules meant that this situation was not justifiable. The APPG did not believe that the recently updated DWP guidance on the Special Rules for clinicians would sufficiently improve the experience of terminally ill people, and that while the six-month rule remained, it would continue to lead to terminally ill people being excluded from fast-track access to the financial support they need.

Accordingly, the report made three recommendations:

- The UK Government should amend the definition of terminal illness in UK law so that a person is determined as having a terminal illness if it is the clinical judgment of a registered medical practitioner or clinical nurse specialist that they have a progressive disease that can reasonably be expected to cause the individual’s death. The APPG called on MPs to support Madeleine Moon MP’s Private Member’s Bill, the Access to Welfare (Terminal Illness Definition) Bill, to achieve this.
- The DWP should adopt the same approach it has taken for severe conditions and adopt a “light-touch” review of benefit awards under the Special Rules after 10 years, with the DWP contacting the claimant’s GP to confirm that their diagnosis and prognosis remains the same. This would “spare the very small minority of people who are fortunate enough to live for three years with a terminal illness from having to unnecessarily re-apply for their benefits.”
- The DWP should immediately end the practice of non-specialist DWP assessors challenging and rejecting the medical evidence provided by clinicians in a DS1500 form to support a benefit claim under the Special Rules. The APPG had been greatly concerned to learn about this practice, which it felt was unjustifiable and gave lie to the DWP’s assertion that it treats the claims of terminally ill people with “the utmost sensitivity and care.”

6.4

Welfare (Terminal Illness) Bill 2019-21

On 22 July 2020 a Private Member's Bill – [Welfare \(Terminal Illness Definition\) Bill](#) – received its First Reading in the House of Commons. The Bill, introduced by Jessica Morden MP, would make provision about terminally ill people in the welfare system. Speaking at the First Reading, Jessica Morden outlined the intentions of her Bill:

The aim of this Bill is to encourage the Government to address the failures of the special rules for terminal illness, which do not fast-track some terminally ill people for benefits, and to make it easier for terminally people to access the benefits that they need. In particular, it addresses the need for urgent action to reform two aspects of the special-rules guidelines that are a source of distress and difficulty for people living with terminal illness. They are the six-month rule which, under section 82 of the Welfare Reform Act 2012, obligates someone to provide medical proof that they have six months or less to live so that they can access benefits quickly and at a higher rate; and the three-year award—a Department for Work and Pensions guideline forces terminally ill people to reapply for benefits if they live longer than three years after the benefit is awarded. As I hope to outline clearly, those two deeply unfair rules are the source of much distress and anguish for individuals and families dealing with the shattering consequences of terminal illnesses such as motor neurone disease, terminal cancers, advanced lung and heart conditions and a range of neurological conditions, which are equally affected.⁸⁶

The Bill did not progress further.

⁸⁶ [HC Deb 22 July 2020 c2194](#)

7 Scottish changes

The Scottish Government has introduced a new definition of terminal illness, along with guidance to support clinicians to interpret and apply the new rules. For the suite of new benefits being rolled out in Scotland from Summer 2021 to replace DLA, PIP and Attendance Allowance, a new Benefits Assessment under Special Rules in Scotland (BASRiS) will replace the DS1500. This will not apply to Universal Credit and ESA, which are reserved benefits under the control of the UK Government.

7.1 The debate around changing the definition

In 2018, during the passage through the Scottish Parliament of the Social Security (Scotland) Bill – which would transpose the benefits to be devolved (including disability benefits) onto a Scottish legislative platform – 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 Conservative MSP Jeremy Balfour, and had the support of Labour and Green MSPs.

The Scottish Government indicated that 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 proposed further changes to the rules to include additional circumstances in which someone could be eligible for assistance under the terminal illness rules.⁸⁷

Only two days later however, the then Minister for Social Security, Jeane Freeman, announced a change in the Scottish Government’s position.⁸⁸ The Minister noted that while the medical professional organisations, Scotland’s Chief Medical Officer and its Chief Nursing Officer had made it clear that, because of the complexities involved, two years was too long, “...they and I also know very well that the UK Government’s current 6 month limit excludes

⁸⁷ [Letter from Jeane Freeman MSP, Minister for Social Security, to the Convenor of the Scottish Parliament Social Security Committee](#), 18 April 2018

⁸⁸ See the Scottish Government press release, [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

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.⁸⁹

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 (i.e. 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.⁹⁰

7.2 Introducing the new rules to Scottish benefits

On 28 February 2019 the Scottish Government published Terminal illness and Disability Assistance: a policy position paper.⁹¹ This gives information on consultations and other activity in relation to the development of the CMO's guidance. The guidance itself was published in June 2021, in advance of Social Security Scotland (the new Scottish social security agency) delivering the first form of Disability Assistance.

The Scottish Government's intention had been to introduce Child Disability Payments (replacing DLA) from summer 2020, and to introduce benefits for disabled adults from early 2021. However, due to the coronavirus crisis, the introduction of these benefits was delayed.⁹²

In November 2020, the Scottish Government [announced](#) that Adult Disability Payment would be rolled out for new claims by Summer 2022 with a pilot in

⁸⁹ Ibid

⁹⁰ Schedule 5, Section 1(2) of [The Social Security \(Scotland\) Act 2018](#)

⁹¹ Scottish Government Social Security Directorate, [Terminal Illness and Disability Assistance: policy position paper](#), 28 February 2019

⁹² The Scottish Government, [Disability Assistance](#) (accessed 5 August 2020)

the spring, and that Child Disability Payment would replace Disability Living Allowance for children in summer 2021.⁹³

The terminal illness guidance for medical professionals required under the 2018 Act was subject to a closed consultation during 2019. In advance of the rollout of Child Disability Payment, Social Security Scotland published guidance for clinicians. This introduces the new Benefits Assessment for Special Rules in Scotland (BASRiS) form, which is replacing the DS1500 for Scotland's new forms of disability assistance.⁹⁴

Alongside this, Social Security Scotland also published a [range of guidance documents](#) on the new rules, including:

- [Frequently asked questions](#) for clinicians
- [Guidance on when to complete a BASRiS or DS1500 form](#)
- [A leaflet for patients](#)

7.3 Allowing other medical professionals to complete forms

On 1 May 2020, the Social Security Administration and Tribunal Membership (Scotland) Bill was introduced in the Scottish Parliament. Among other things, the Bill would allow medical professionals other than doctors to confirm that a person is terminally ill for the purpose of 'fast tracking' their benefit claim.⁹⁵

The [Social Security Administration and Tribunal Membership \(Scotland\) Act 2020](#) received Royal Assent on 10 November 2020. Previous provision in [Schedule 5 of the Social Security \(Scotland\) Act 2018](#) had restricted this to 'registered medical practitioners' (i.e. doctors).

7.4 Scope of Scottish changes

Only certain benefits accessible through SRTI have been devolved to Scotland. Under the Scotland Act 2016, responsibility for some disability benefits – including DLA, PIP and Attendance Allowance – was devolved to the Scottish Government and Parliament. ESA and Universal Credit (except the housing

⁹³ The Scottish Government, [Social Security benefits - update: statement by the Cabinet Secretary for Social Security and Older People](#), 17 November 2020

⁹⁴ Chief Medical Officer, [Chief Medical Officer's guidance for clinicians completing a BASRiS form](#), 29 June 2021

⁹⁵ See Scottish Parliament Information Centre, [Social Security Administration and Tribunal Membership \(Scotland\) Bill](#), 1 May 2020, p10

element, and payment arrangements) are not devolved and remain the responsibility of the UK Government.

Consequently, changes to the definition and practice in Scotland create a two-tier system where claimants have to meet different definitions to apply for devolved and reserved benefits under the Special Rules.

Reflecting on the two-tier system changes in Scotland are bringing about, the APPG for Terminal Illness argued in 2019 that the Scottish model ought to be adopted UK-wide:

The overwhelming majority of evidence submitted to the APPG's inquiry supports aligning the UK definition of terminal illness with the incoming Scottish law, both from a desire to avoid a two-tier system in Scotland and to ensure that the benefits system does not continue to fail terminally ill people in desperate need of financial support.⁹⁶

⁹⁶ APPG for Terminal Illness, [6 Months Left to Live2](#), July 2019, p47

8 UK Government changes

On 11 July 2019 the then Secretary of State for Work and Pensions, Amber Rudd, announced that she had 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.”⁹⁷

A DWP press release noted that not all doctors understand the system or feel confident they are making the right diagnosis for their patients, and that the rules are often seen as favouring those living with cancer when other illnesses can also limit life. For those living with the most severe or progressive conditions, benefit processes had recently been made simpler, reducing “unnecessary reassessments.”⁹⁸ However, the Secretary of State wanted “to look again to make sure that 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”, and she had ordered her Department to seek the views of a wide range of people, including patients, doctors and nurses.

Justin Tomlinson, the Minister for Disabled People, said of the evaluation in an oral answer to the House:

We understand the importance of the issue, and we are doing internal research with clinicians and external research with claimants and stakeholders. We are also looking at international research, which will include what the Scottish Government are doing, and we will be concentrating on the process to ensure that it is improved.⁹⁹

The evaluation included three strands of research:

- Hearing directly from claimants and charities about their first-hand experiences.
- Considering international evidence to find out what works in other nations and the support they provide.
- Reviewing current DWP performance to better understand how the Special Rules for Terminal Illness and Severe Conditions processes operate and perform.

⁹⁷ DW Press release, [Terminally ill benefit claimants deserve a fresh and honest evaluation of the way the system supports them](#), 11 July 2019

⁹⁸ For details of these changes see [ESA and PIP reassessments, Commons Library Briefing Paper CBP-7820, 10 May 2019](#)

⁹⁹ [HC Deb 7 October 2019 cc1477-8](#)

On 8 July 2021, Justin Tomlinson provided a written statement to the House of Commons¹⁰⁰ and the DWP published a press release announcing that 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 12-month, end of life definition.”¹⁰¹ The Government says that this “will mirror the current definition of end of life used across the NHS and ensure that people receive vital support through the Special Rules six months earlier than they do now.”¹⁰²

This change will eventually apply across all benefits to which the current terminal illness rules apply, but will begin in 2022 with income-replacement benefits: Universal Credit and New Style Employment and Support Allowance. Extra costs disability benefits such as Personal Independence Payment will follow “when parliamentary time allows”.

The decision 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.

[Findings from the evaluation of the Special Rules for Terminal Illness process](#) were published alongside the Health and Disability Green Paper on 20 July 2021. This outlined responses from clinicians to the consultation and provided a fuller explanation for the shift to a 12 month definition:

42. The 12-month definition of the ‘end of life’ period was originally developed by a group of 21 organisations including the General Medical Council (GMC), the Department for Health and Social Care and national charities. Aligning with this approach will enable the DWP to align with existing standards and approaches used in the Health and Care sector. GPs are encouraged to identify who among their patients is likely to be in their final year of life, and in the survey of clinicians moving to a 12-month prognosis period as the eligibility criteria for accessing benefits via the Special Rules was the option with the highest level of support. Our conversations with clinicians also demonstrated significant support for aligning the definition used in the welfare system with the 12-month definition of ‘end of life’ used in the NHS and by the GMC. It is fair and compassionate to frame the fast-tracked procedure for all individuals who are approaching the end of their lives in a way that reflects current clinical practice. There are a number of benefits to aligning with the NHS, including reducing the need for clinicians to have multiple difficult conversations with people nearing the end of their lives. It also provides opportunities to take advantage of existing NHS initiatives to identify people in their final year of life and for clinicians

¹⁰⁰ [HCWS166, 8 July 2021.](#)

¹⁰¹ DWP, [Fast-tracked access to benefits for people with terminal illness expanded](#), 8 July 2021

¹⁰² [HCWS166, 8 July 2021.](#)

to consider whether financial support is required and to support the person to make a Special Rules claim to benefits.¹⁰³

¹⁰³ DWP, [Findings from the evaluation of the Special Rules for Terminal Illness process](#), 20 July 2021

9

Northern Ireland

On 6 October 2020, 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.”¹⁰⁴

A 30 June 2021 written statement from Dierdre Hargey, the Minister for Communities, confirmed that the definition of terminal illness would be extended from six to 12 months. The Minister explained:

I have secured Executive agreement to my planned approach to amend social security legislation to widen the eligibility definition in the special rules for terminal illness.

The changes I will make will apply to all of the five social security benefits to which the special rules apply.

This is an important step forward that will mean more people who find themselves in the devastating position of being terminally ill will benefit from fast-tracked access to financial support through social security benefits. They will not have to go through assessments and will get automatic access to benefits earlier.

Changing the provisions around the special rules will require amendment to both primary and secondary legislation. I know that Assembly colleagues across all parties have expressed concern about the current legislative provision and I hope that you will all work with me so we can deliver change as quickly as possible.

I can reassure you that through the legislative process my Departmental officials will continue to actively and positively engage with key stakeholders, advocacy groups and the clinical community.

I will keep these provisions under review and consider further options for reform in the future. This will include monitoring international best practice, reviewing the definition of special rules and looking at a clinically led model in the time ahead.

I am committed to making real change to the status quo in order to put in place a system that lessens the stress and anxiety for people during the most difficult times.¹⁰⁵

¹⁰⁴ [Northern Ireland Assembly, 6 October 2020](#)

¹⁰⁵ Department for Communities, [Changing the Special Rules for Terminal Illness \(SRTI\)](#), 30 June 2021

In July 2020, the High Court of Justice in Northern Ireland found that the difference in treatment for a claimant who was unable to demonstrate that their death could reasonably be expected within six months, compared to one who could demonstrate this but nonetheless survived longer, was “manifestly without reasonable justification”. This, Justice McAlinden found, constituted a breach of Article 14 of the European Convention on Human Rights within the ambit of Article 8 and Article 1 Protocol 1.¹⁰⁶

The claimant, Lorraine Cox, was later awarded £5,000 for the “upset, distress, annoyance, inconvenience, worry and humiliation” caused as a result of unlawful discrimination.¹⁰⁷

The Department for Communities¹⁰⁸ and the DWP subsequently appealed the judgment to the Court of Appeal in Northern Ireland. On 3 August 2021, the Court of Appeal delivered a judgment which overturned the High Court’s decision that difference in treatment constituted a breach of Article 14. Lord Chief Justice Morgan found that that allowing people to access the Special Rules on the basis of a diagnosis of a progressive illness, would change the nature of the rules:

[...] the extension of the SRTI to those who have a diagnosis of a progressive illness as a consequence of which death can reasonably be expected would change the basis for the award of the benefit. It would no longer be needs based. It would be determined by the diagnosis of a particular condition independently of need.

He went on to argue that this is a political matter, and not one for the courts to decide, particularly since the policy had been considered in the legislature and the intention to adopt a twelve-month definition had been announced:

[...] That is plainly a controversial political matter which it is not for the courts to determine.

[74] In this area of welfare benefits substantial weight is generally accorded to the primary decision maker. We do not accept that this is a case in which the difference of treatment is based on a suspect ground such as sex or religion. We accept that a relatively strict approach has been taken in cases concerned with persons with disabilities in order to foster their full participation and integration in society. That objective is honoured in this case by the application process based on need. This is not a case where the applicant has been excluded from the benefit.

[75] The legislature has been involved in a detailed consideration of where to draw the line in this welfare benefit in 1990 and 2010. There has been continuing review of that decision since 2018. The Minister

¹⁰⁶ [2020] NIQB

¹⁰⁷ Law Centre Northern Ireland, [Terminally Ill Woman Receives Award for ‘Distress and Humiliation’ Caused by Terminal Illness Rules](#), 22 October 2020

¹⁰⁸ Which administers benefits in Northern Ireland

intends to submit a further proposed amendment to the Northern Ireland Assembly which will provide an opportunity for debate and reflection by the legislature. This is an area where considerable weight should be given to the views of the primary decision maker. These choices are for the political process and not for the courts.¹⁰⁹

¹⁰⁹ [\[2021\] NICA](#)

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