

Benefits Bulletin

Special Rules...

10th May 2023

Issue **5** [2023]

Terminal Illness

The rules surrounding benefits and terminal illness have changed. For 'special rules' benefit purposes a person was previously considered to be 'terminally ill' (see below) if their life expectancy was considered to be less than six months. However, the six-month time limit has now been extended to 12-months.

This means that more people nearing end of life will be able to access benefit entitlement earlier, more easily and at a faster pace.

Special Rules - Terminal illness: A person will now be considered to be '*terminally ill*' if at that time they suffer from a progressive disease and their death in consequence of that disease can reasonably be expected within 12 months (not six months).

For over 30 years people who have been considered to be 'terminally ill' have had passported rights to certain benefits. Presently depending upon a person's age and personal circumstance they may access:

- the Disability Living Allowance (DLA) higher rate care component - worth £101.75 per week

- the Personal Independence Payment (PIP) enhanced rate daily living component - worth £101.75 per week
- Attendance Allowance (AA) at the higher rate - worth £101.75 per week.



A new SR1 Form to replace the old DS1500 Form...

In addition, for the purposes of Universal Credit and Employment and Support Allowance (ESA) it means that a person may, under the Work Capability Assessment (WCA) be treated as though they have 'limited capability for work' and 'limited capability for work-related activity'.

This means that for Employment and Support Allowance the person will get the Support Component (worth £44.70 per week) immediately. For Universal Credit it means that any award will include the Limited Capability for Work and Work-Related Activity Element (worth up to £390.06 per month) and the person will not be subjected to the 'work-related requirements' of having to look for work, be available for work, etc.

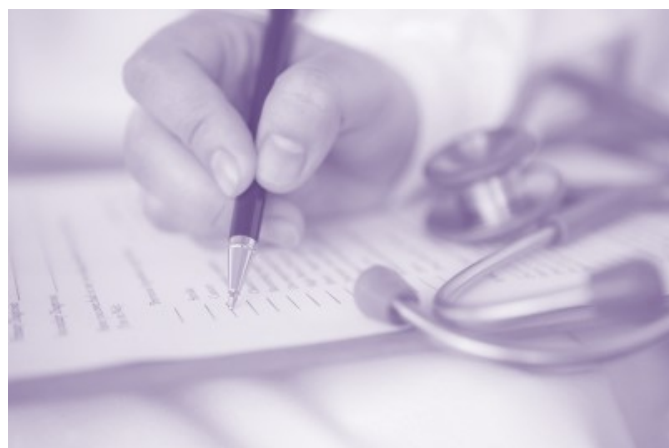
The new 12-month 'special rules' were applied to the Work Capability Assessment from 4th April 2022. The same extension was applied to DLA / PIP / AA from 3rd April 2023.

Please see this [LINK](#) for more information.

New SR1 Form

The 'special rules' system has included a 'special rules' priority system for claims and a shortened claim process. The fast-track system has been triggered by use of a DS1500 terminal illness form. This form has now been replaced by a new SR1 end of life form.

The SR1 Form can be obtained from a person's General Practitioner (GP) or the hospital where they are being treated or the hospice where they may be staying.



The SR1 Form replaced the DS1500 Form for DLA / PIP / AA purposes from the 3rd April 2023. However, the SR1 Form replaced the DS1500 Form for the Work Capability Assessment since 4th April 2022.

Background to the changes...

The six-month special rules fast-tracked support system for people nearing the end of life was first introduced in 1990. However, it has long since been the subject of criticism and was the subject of an evaluation review in July 2021 involving claimants, medical professionals and other stakeholders.

The evaluation review found that the existing system was 'not fit for purpose' and was in need of change. It found that the 6-month rule:

- made it difficult for medical professionals to make a clear prognosis where variable conditions were present; and
- caused difficult conversations between clinicians and patients about issues of life expectancy at a time which could be distressing for both individuals and their families.

It was noted that these difficulties could be particularly present in cases of people with Motor Neurone Disease (MND).

The evaluation review concluded that it was only fair and compassionate to align the definition used in the welfare benefit system with the 12-month definition of 'end of life', used in the NHS and by the General Medical Council and in current clinical practice.

Please see [Findings from the evaluation of the Special Rules for Terminal Illness process](#) (dated 20th July 2021) for more information.

It is understood that the rule change to ESA happened sooner than that to DLA / PIP / AA because it only involved a change to the regulations: [The Universal Credit and Employment and Support Allowance \(Terminal Illness\) \(Amendment\) Regulations 2022](#) (Statutory Instrument 2022 No. 260). Whereas, the rule change to DLA / PIP / AA took longer because it involved a change by act of Parliament: [Social Security \(Special Rules for End of Life\) Act 2022](#).

No Reasonable Justification...

In July 2020 in the High Court of Justice (Northern Ireland) Ms Lorraine Cox challenged the then terminal illness special rules under which Personal Independence Payment (PIP) could be claimed.

Ms Cox was a lone parent of 3 young children. She had been given a definitive diagnosis of Motor Neurone Disease. At the material time it was estimated that she had a life expectancy of between two to five years.

Her original application for Personal Independence Payment (PIP) made in March 2018 was refused. Following her application for a 'mandatory reconsideration' she was awarded the standard rate of the 'daily living component' as opposed to the enhanced rate which would have been awarded if she had been able to meet the terminally ill rules as they stood. When she appealed against this decision in an attempt to obtain payment of the 'enhanced rate' of the 'daily living component', the appeal tribunal refused the appeal.

Eventually, in November 2019 Ms Cox was awarded the enhanced rate of the 'daily living component' and the standard rate of the 'mobility component' from April 2019 to January 2022 based on a recognised increased care needs and mobility difficulties.

Her case before the High Court was that the special rules on terminal illness were discriminatory from the perspective of an individual who was diagnosed as suffering from a terminal illness but whose expected life expectancy was greater than six months.

After careful analysis of the special rules the High Court held that it could find nothing to justify or explain why those individuals who have a terminal diagnosis but are not expected to die within six months and those individuals with a terminal diagnosis and who are reasonably expected to die within six months but who survive beyond that six-month period, are treated differently.

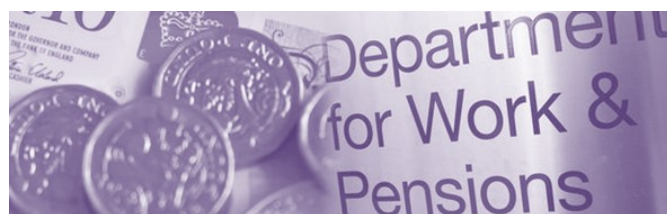
It held that there was nothing that could be found to justify or explain why those with a life expectancy of less than six months (but who may live longer) have immediate access to benefits but those who are terminally ill but have a life expectancy of more than six months did not.

In final analysis the High Court held that it could find no evidence, justification or rationale to explain why Ms Cox was not deemed to be entitled to the 'enhanced rate' of the 'daily living component' from the date when her terminal diagnosis was confirmed. This difference in treatment is manifestly without reasonable justification and was therefore, in breach of the European Convention of Human Rights.

Note: The case also examined the inequalities in the treatment of people with degenerative life ending conditions under Universal Credit and the differing amounts of Universal Credit paid. In this respect the High Court held it could find no evidence, justification or rationale to explain why an applicant who was terminally ill could not be deemed to be entitled to the 'limited capability for work-related activity element' from the date on which they made their claim for Universal Credit.

Please see [\[2020\] NIQB - Reference McA11286 \(2019/116363\) - Judicial Review](#) (dated 7th July 2020 - Justice Gerry McAlinden) for details of the full judgement.

It is estimated that an extra 45,000 Special Rules cases will arise as a result of the new provisions, costing the DWP £115 million per year in extra disability and income-replacement benefit claims by 2026/2027.



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