

Claiming disability benefits under the Special Rules for Terminal Illness

Briefing by the MND Association, March 2019

Background

The Special Rules for Terminal Illness (SRTI) application process is intended to enable claimants who are terminally ill to access disability benefits rapidly, without going through the standard application process. The SRTI application route is available for Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Attendance Allowance and Universal Credit (UC).

An SRTI application requires that the individual's doctor, consultant or specialist nurse submits a medical form (the DS1500). Successful SRTI applications enable the claimant to access higher rate of benefits more quickly (including the enhanced daily living component of PIP, but not the mobility element) without waiting for any qualifying periods to come to an end, having to fill in a long form or undergo a face-to-face assessment. It also exempts people who are terminally ill from the requirement under Universal Credit for claimants to discuss their work aspirations with a work coach.

Issues

The primary issue with the SRTI process is its restrictive eligibility criteria, which limit access to the process and force many people living with terminal conditions to apply via the standard application process. The standard process is extremely burdensome and time-consuming for a person dealing with the devastating emotional and physical impact of a diagnosis of a terminal condition such as motor neurone disease (MND).

The eligibility rules for the SRTI process are set out in the Welfare Reform Act 2012, which states that: "a person is "terminally ill" at any time if at that time the person suffers from a progressive disease and the person's death in consequence of that disease can reasonably be expected within 6 months." ([Welfare Reform Act 2012, Part 4](#)).

This definition means that the SRTI process is problematic for a number of reasons:

- 1) The timescale is short compared to the progression of some terminal illnesses.
- 2) The definition does not reflect the difficulty of providing an accurate prognosis for individuals living with complex terminal illnesses.
- 3) Health professionals' interpretations of the definition vary significantly, leading to inequity of access.
- 4) Health professionals have reported that assessors contact them to question submitted DS1500 forms.

1) The timescale is short compared to the progression of some terminal illnesses

The requirement for a "reasonable expectation" of death within six months, if strictly interpreted as a prognosis of six months or less, can exclude many people living with terminal and highly disabling conditions.

In the case of MND, for example, a common prognosis is for a life expectancy of 1-5 years, which reflects the difficulty of providing a precise prognosis for individuals living with the

condition. Around a third will die within one year and more than half within two years of diagnosis. However, the SRTI process is far more suitable for people with a diagnosis of MND than the standard application process.

People living with MND have to cope with a devastating diagnosis of a condition that is terminal in all cases, progresses unpredictably and often rapidly, and causes major and progressive disability. The SRTI route can provide rapid access to the vital support they urgently require, unlike the standard process, which is difficult and time-consuming to complete and in the case of PIP includes a 3-month qualifying period. It is unfair to ask some people with terminal illnesses to apply through the 'normal rules' because they might have a slightly longer life expectancy than others, or because it is not possible to accurately predict that they are in the last six months of life.

2) The 6-month definition does not reflect the difficulty of providing an accurate prognosis for individuals living with complex terminal illnesses

MND is a highly complex condition, and MND progression is extremely variable and difficult to predict. With our current level of understanding of MND it is not possible to give a precise prognosis of life expectancy in individual cases. There is therefore a need to allow for a sensible degree of flexibility in cases where an individual is living with an unpredictable terminal condition.

Individuals with a confirmed terminal diagnosis should not be unfairly excluded from the SRTI process because they have a less predictable or less well-understood form of terminal illness. The current language around SRTI eligibility wrongly assumes that life expectancy can be accurately estimated for people living with terminal illness. [Research from the Marie Curie Palliative Care Research Department](#), University College London, examined the accuracy of over 8,000 prognostic estimates for terminally ill patients in the UK. It found that accuracy varied from 23% to 78%.

3) Health professionals' interpretations of the definition vary significantly, leading to inequity of access

As a result of the inherent unpredictability of MND described in point 2) above, professionals treating people with MND have a difficult judgment to make when asked to sign a DS1500 form. Consequently, there is variation in how the SRTI criteria are interpreted and in doctors' willingness to submit the form for people with MND. Some interpret the criteria broadly enough to submit the form on behalf of the majority of claimants with MND, while others feel that the current criteria restrict their ability to support SRTI applications in many cases. As a result, claimants' access to the SRTI process depends to a large extent on the attitude and interpretation of individual clinicians, leading to variation and inequity of access. More flexible criteria would give doctors more confidence to support SRTI claims for people with a terminal condition such as MND.

A recent independent poll¹ of over a thousand GPs found that 51% supported a change in the definition of a terminal illness for claiming benefits under special rules. Only 12% oppose it. In light of these findings it is clear that the current definition is problematic for the health professionals trying to apply it.

¹ Commissioned by the MND Association and carried out by MedeConnect in their GP Omnibus Survey, October 2018.

4) Health professionals have reported that assessors contact them to question submitted DS1500 forms

Some doctors and other health professionals have told the MND Association that they have been contacted by disability assessors or the DWP querying the validity of a submitted DS1500 form. To inform the [MND All-Party Parliamentary Group's 2017 report on PIP](#), the MND Association contacted clinicians and care coordinators at MND Care Centres to ask for their experiences of supporting SRTI claims. Out of 21 health professionals who responded, 13 said they had been contacted by assessors questioning prognosis for a PIP claim under SRTI.

One told us that "I frequently have calls from [assessment provider] after filling in the DS1500, asking if they have a terminal illness." Another stated that "we have tried to complete DS1500 forms for people with MND previously and it has been rejected, because the PIP assessors have decided they are expected to live longer than 6 months."

We believe that the Department should make it clear to assessment providers and its own staff that they are not qualified to question or challenge the judgment of a specialist health professional with condition-specific experience and expertise when processing SRTI applications.

People who are terminally ill are expected to meet work coaches under Universal Credit

The UC customer journey does not include specific accommodations for claimants with disabilities or vulnerabilities. As a result, people who are terminally ill but have more than six months to live, including some people with MND, will be asked to attend work-focused interviews at a JobCentre Plus with a work coach in order to determine what work they can do and to agree a claimant commitment. This is not only a waste of time and public resources but demeaning and insulting to a person who has had to give up work because of a progressive and terminal illness. Claimants applying via SRTI will not be expected to undergo these procedures. However, under the current regulations the majority of claimants with MND will not be able to apply through SRTI and consequently will be exposed to highly inappropriate work coaching requirements.

What should change?

Last year, the Scottish Parliament passed the Social Security (Scotland) Act which changes the definition of terminal illness to one based on clinical judgement, thus removing the 6-month restriction. So, a claimant is determined as having a terminal illness 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 understand that guidance is now being developed in Scotland to bring further clarity to how this change should be applied.

This will create a much fairer system in Scotland where people with a terminal illness with more than six months to live will qualify for SRTI. We would strongly support a similar legislative change to create a fairer system in all nations within the UK.

The SRTI process is for the most part effective and appropriate for people with terminal conditions. Its chief failing is that many people living with unpredictable terminal conditions are not able to use it, leaving them to struggle through a claims process that is entirely inappropriate for their situation. We call on the DWP to address this significant flaw as a matter of urgency.

Private Members' Bill

In July 2018, Madeleine Moon MP presented a Ten-Minute Rule Bill titled "[Access to Welfare \(Terminal Illness Definition\) Bill 2017-19](#)". The Bill proposes to replace the requirement of 'reasonable expectation of death within six months' with a clinical judgment made by an appropriate health professional. In effect, the Bill would replicate the change made in Scotland and apply the same change to the rest of the UK.

The Bill passed First Reading on July 18th 2018 and is due its Second Reading on 22 March 2019. The MND Association is calling on all MPs to support the Bill.

Work and Pensions Select Committee

The House of Commons Work and Pensions Select Committee [published a report](#) on Universal Credit in December 2018, which recommended that the Government adopt the change proposed by Madeleine Moon's Bill. The report states:

'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".'

Proposed revisions to DS1500 guidance notes

In response to our campaign, the DWP in January 2019 proposed a range of revisions to the DS1500 guidance, aimed at softening the language around the six-month requirement. The proposed revisions represent an improvement to the guidance and reflect the progress made through our campaign to draw attention to the flaws of the Special Rules process as it stands.

However, the retention of the six-month rule in legislation limits the Department's ability to improve the Special Rules system. The proposed new guidance will continue to make reference to the six-month criterion, limiting the impact of the revisions and allowing ongoing uncertainty around inherently unpredictable terminal conditions, such as MND. In addition, due to the legislative changes passed in Scotland in 2018, a two-tier system will develop unless the rest of the UK makes a similar change to the law. For these reasons, we continue to argue that a change to UK law is necessary to finally resolve this issue and ensure that all those who are terminally ill can access the benefits they need rapidly and sensitively.

About MND and the MND Association

1. Few conditions are as devastating as MND. It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
2. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

3. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
4. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK.
5. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

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