

BW 01

Ymchwiliad i Fudd-daliadau yng Nghymru: opsiynau i'w cyflawni'n well

Inquiry into Benefits in Wales: options for better delivery

Ymateb gan: Cymdeithas clefyd motor niwron

Response from: Motor Neurone Disease Association (MND)

- I. The Association is pleased to have the opportunity to respond to the Equality, Local Government and Communities Committee's consultation. Whilst the Association does not hold a position as to whether benefits should be devolved to Wales, our response highlights the changes we are campaigning for in Westminster, which the Welsh Government could consider adopting if benefits were to be devolved. These changes could have a positive impact on people living with and affected by motor neurone disease (MND) in Wales.

Principles that could underpin the delivery of benefits in Wales

- II. The Association believes that potential devolution of benefits to Wales could provide the opportunity to create a fairer and more compassionate system for people living with progressive and terminal conditions in Wales, including those living with MND. This could be achieved should Wales gain the power to improve access to the Special Rules for Terminal Illness (SRTI) fast-track process that already exists within the welfare system, by changing the legislation that defines a terminal illness for the purpose of accessing benefits.
- III. The SRTI application process as it currently works in legislation is intended to enable claimants who are terminally ill to access disability benefits rapidly, without going through the standard application process. It 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 rates 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.
- IV. The primary issue with the SRTI process in its current form 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 route. This 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).
- V. The current 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).

- VI. 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.
- VII. Whilst the SRTI process is for the most part effective and appropriate for people with terminal conditions, its chief failing is that currently 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. At the time of writing, the UK Government in Westminster does not support a change to the relevant legislation.
- VIII. If this area of responsibility were to be devolved to Wales, it would provide a separate opportunity for a change in legislation to improve access to the SRTI process for people living with complex and unpredictable terminal illnesses such as MND. As will be discussed below, Wales could adopt this change in a similar way that Scotland has through the increased devolution of welfare.

Lessons learned from the devolution of some social security powers to Scotland

- IX. In 2018, the Scottish Parliament passed the Social Security (Scotland) Act which changed the definition of terminal illness for the purposes of accessing welfare to one based on clinical judgement, thus removing the 6-month restriction. In Scotland, a claimant is now 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 at the time of writing, guidance is now under consultation in Scotland to bring further clarity to how this change should be applied.
- X. 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. With devolution, Wales could be presented with a similar opportunity to make the benefits system fairer and more compassionate for people living with terminal illnesses.

Practical considerations of devolution

- XI. If devolution of benefits to Wales were to occur, particular care would need to be taken if this were only partial devolution of certain benefits. This has been a key issue with the devolution of some benefits to Scotland in relation to SRTI. Essentially, in Scotland some of the benefits that the SRTI process can be used for are devolved (PIP and Attendance Allowance), and others are reserved (ESA and Universal Credit). This means there are now two working definitions of a terminal illness for the purpose of accessing benefits in Scotland. The Association would therefore caution that with devolution comes the risk of duplication as well as the risk of making the system more complex than it already is. This would need to be a consideration in light of potential future devolution in this area to Wales.

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.