

**WELFARE REFORM COMMITTEE**  
**THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND**  
**WRITTEN SUBMISSION FROM MND SCOTLAND**

About Motor Neurone Disease

Motor Neurone Disease (MND) is a rapidly progressing, terminal, neurological disease. Approximately 130 people in Scotland are diagnosed with MND each year, yet because of its poor prognosis, just more than 400 people have the illness at any one time. Average life expectancy is only 14 months after diagnosis.

During the course of the illness, people with MND will usually rapidly become severely disabled with symptoms including losing their ability to walk, speak, feed themselves and breathe unaided. Their health will only deteriorate and they will not experience periods of improvement, as is potentially the case with other life limiting illnesses.

Personal Independence Payment

- Many people with MND cannot make the telephone call necessary to start the new claim process as they are unable to speak. There should be a system in place for paper claims. Alternatively, professionals should be able to make a claim on their client's behalf without the client having to give permission over the phone.
- As described in the section above, MND is a rapidly progressing terminal illness. We believe that all people with MND should be automatically awarded PIP without medical assessment. Currently, only those deemed to have 6 months or less to live are 'fast tracked' once a DWP DS1500 form has been completed. However, there are many problems with the DS1500 system:
  - During the initial telephone call, clients are asked if they have a terminal illness. Some are then told to get a DS1500. However, the terms of the DS1500 are often not fully explained and sometimes people are told they must only have 6 months left to live. This is, understandably, very distressing for people who have just been given a terminal diagnosis and many are put off taking the claim any further.
  - Not only is it difficult for patients to talk about DS1500 forms with the DWP but many health professionals are wary of discussing the form with their patients, following such a devastating diagnosis, for fear of distressing them even further. In addition, many health professionals are uncomfortable with having to predict how long their patient may or may not live and are therefore reluctant to complete the DS1500 form. Delays, in turn, cause problems for the patient with MND.

- Even with a DS1500 form in place, a person will wait a long time for their benefit. Receipt of benefit for people with MND used to take up to 7 months and while we are pleased to see this recently drop to an average of 3 months, this is still too long for someone with such short life expectancy.
- People currently receiving DLA for a pre-existing condition, who are then diagnosed with MND must stop their DLA claim and start claiming PIP. However, DLA takes 4 weeks or more to close down and PIP will not be put in payment until this process is complete and a decision has been made on their PIP claim. These clients are losing out on 4 weeks or more of potential increased benefits they are entitled to. This includes those issued with a DS1500 from diagnosis who should be automatically awarded the enhanced rate of the daily living component from the date of the change of circumstance.
- Those who have an award of PIP and then turn 65 years should be considered for a revision of the mobility component and not only the daily living component.

### Carers Allowance

- The earnings limit should be increased from the present £110 a week to allow carers to take on part time work – for many a source of respite from caring and keeping them in touch with the workplace. Many will be required to return to the workplace following the loss of their loved one with MND.
- Carers Allowance should not overlap with other benefits, in particular, the State Pension. Many carers are older in years, as people are generally living longer, but they cannot receive Carers Allowance due to being in receipt of the State Pension. This is despite being full time informal carers and receiving no monetary recognition for this – a full time role which is saving the local authorities/NHS considerable care costs. In addition, older carers are more likely to become ill themselves and, arguably, require more financial support, not less.

### Universal Credit

- Paper claims should be allowed. Currently claims must be online. However, not all clients can use or have access to computers.
- There is no entitlement to help with mortgage interest if the client is earning. Someone with MND or their carer must stop work completely to get help with this rather than potentially reducing hours or working part time. This is not supporting the Government's "better off in work" policy.

## About MND Scotland

MND Scotland is the only MND charity in Scotland providing care, information, funding for research and a voice for those affected by the illness.