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

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.

Welfare reform and people with MND
A diagnosis of MND is a devastating blow to a family. The consequences of welfare reform can often feel like the last straw during this traumatic time. We can also demonstrate that putting people with MND through this process is illogical and a waste of taxpayers’ money. The implications for people with MND of assessment for Employment and Support Allowance, ‘the Bedroom Tax’, and Personal Independence Payment specifically, are outlined in detail here.

MND Scotland and our welfare reform campaign
MND Scotland is the only Motor Neurone Disease charity in Scotland providing care, information and funding for research. Our services include a dedicated Welfare and Benefits service which provides practical support to people with MND across Scotland.

At the end of April we launched a welfare reform campaign which included a briefing report called ‘Time to benefit people with MND’. This has been sent to the Secretary of State for Work and Pensions, Iain Duncan Smith MP and Lord Freud, Minister for Welfare Reform. The content of this report forms the basis of our Your Say submission.

Employment & Support Allowance
Under Incapacity Benefit, people with MND were exempt from going through a medical assessment and awarded the full benefit from the outset. This exemption was removed when Incapacity Benefit was replaced by Employment and Support Allowance (ESA) in 2008.
When applying for ESA, everyone with MND needs to go through the Work Capability Assessment (WCA). Following the initial WCA questionnaire assessment, some people with MND are being assigned to the Support Group and awarded full benefit indefinitely, yet many others are being put through the medical assessment. Some of those are being assigned to the Work Related Activity Group instead of the Support Group and face months of sick lines, interviews and reassessment.

Incredibly, many people with MND have been found fit for work and not awarded the benefit at all.

MND Scotland highlights that 100% of people with MND who have received support from our charity’s dedicated Welfare and Benefits service have been assigned to the ESA Support Group and awarded full benefit. This illustrates that putting people with MND through this process is not only causing them stress and anxiety at a very traumatic time – it is clearly an unnecessary cost to the taxpayer.

The 2012 revised DWP WCA handbook specifically acknowledges the severity of MND, notes that there is no treatment to “prevent progression” and suggests that “exceptional circumstances” can be applied to those with the disease going through the WCA, meaning they can be treated as having limited capacity for work.

**Jamie**

Jamie, who is 40 years old, has MND. He lives in the North of Scotland with his wife and 3 year old daughter. Jamie was employed as a mechanical technician but had to give up work when his motor function deteriorated and his arms became very weak. Jamie was assessed for ESA but he failed the WCA. He was only awarded 9 points and deemed fit to work. He appealed the decision but had to wait one year for his appeal to be heard and was only provided with the basic rate of benefit during this time. He eventually won his appeal at tribunal and was awarded a further 22 points. However, Jamie was put into the Work Related Activity Group (WRAG) meaning entitlement to ESA ran out after one year. This meant as soon as Jamie’s benefit was backdated, payment was stopped. With the support of our Welfare Benefits Officer, Jamie applied again. However, the process took 3 months, during which time he received no payment of ESA; a loss of income for the family of almost £100 per week. Eventually, Jamie was moved into the ESA Support Group which meant his benefit was reinstated at the higher rate and backdated. He is unlikely to have to undergo any further assessments.

In our campaign, MND Scotland has called on the DWP & UK Government to exempt people with MND from the WCA, from the outset, as it has now done with
people receiving cancer treatment, allocate them to the ESA Support Group and award full benefit.

**Housing Benefit spare room subsidy / ‘the Bedroom Tax’**

‘The bedroom tax’ has very serious implications for people with MND. As people with MND lose their ability to walk, speak, feed themselves or breathe unaided, they come to rely on a wide variety of equipment to assist them in their daily living. Much of this equipment, such as a wheelchair, special medical bed, hoist, breathing equipment and speaking aids are needed in the bedroom to help the person with MND keep safe during the night. This equipment makes it very difficult for a spouse/partner to sleep in the same room and share a ‘marital bed’. Often, the carer will sleep in a second bedroom and catch some much needed sleep.

In addition, many people with MND have had their homes significantly adapted to meet their specific needs by their local authority. If forced to move, their new home would also need adapted.

MND Scotland, with MNDA, wrote to Secretary of State for Work and Pensions, Iain Duncan Smith MP, urging him to consider revising the scheme so that people with MND are not unjustly penalised. The Government response states that Discretionary Housing Payments (DHPs), administered by local authorities, will be available to priority groups, including those who have had their homes significantly adapted. However, DHPs are variable depending on your local authority, short term and one off payments. They do not present a solution to people with MND who will be competing with other groups for this limited pot of money.

**William**

William, who has MND, and his wife Carol live in the West of Scotland. They have two wheelchairs and their housing association home has been adapted for their needs. William uses a single electric bed and he can only communicate using ipad software. They had been informed that 14% (£11.50) would be deducted each week from their housing benefit because they are deemed to be under-occupying by one bedroom. William is unable to work and Carol is his full time carer so they cannot increase their income to meet this deduction. They will go on the local authority waiting list until a suitable adapted one bedroom property is found or one is adapted for them. William and Carol applied for a DHP from their local authority to meet the shortfall of rent. This was refused. They were supported by our Welfare and Benefits service to appeal this decision. The outcome of this appeal is that they have been awarded DHP but for only a *three month* period. In addition, the DHP awarded only covers *half* of the shortfall - £5.23 per week, so they still need to find another £5.23 per week themselves.
This outcome is very different from another couple, supported by our service, whose circumstances (medical, severity of disability and housing) are almost identical to William and Carol. They also live in the West of Scotland, but in a different local authority area, and had their initial DHP request refused. On appealing this decision, they have now been awarded DHP to cover the full shortfall of £17.40 per week for one year, which has also been backdated to clear arrears. This couple have been advised by their local authority to make another claim once the award ends.

Sharon
Sharon has MND and was informed by her local authority that she would be eligible to pay a Housing Benefit spare room subsidy / ‘bedroom tax’. She lives with her husband in a two bedroom flat. She should have been exempt from paying this as she receives ‘regular’ overnight care from an agency two nights per week. However, she was originally informed by her local authority that she was not exempt as she does not receive this care for seven nights per week. With the support of our Welfare and Benefits service, Sharon appealed and has just been informed that this decision has been overturned and she will be considered exempt.

MND Scotland has called on the DWP and UK Government to exempt from ‘the bedroom tax’ those who:
- are unable to share a bedroom with their spouse/partner due to an array of medical equipment necessary to keep them safe during the night; and those who
- have had their homes significantly adapted. If not, local authorities will potentially be meeting the cost of their housing needs several times over – to adapt their homes in the first instance, provide them with a DHP to offset the loss of housing benefit or find them a smaller home that would need to be specially adapted all over again.

Personal Independence Payment
From June 2013 people who receive a diagnosis of MND will be assessed for Personal Independence Payment (PIP). From October, those who currently receive Disability Living Allowance (DLA) and report a change in their illness will be reassessed for PIP.

Under PIP, due to the loss of a lower rate of benefit, many people with MND in the early stages of their illness will lose out financially. As MND is such a rapidly progressing illness, once the disease has reached the stage necessary to qualify for
standard and then enhanced rate of PIP, a person with MND may not have many months left to live.

People with MND who currently receive the higher rate mobility and care components of DLA will have to go through the full PIP assessment like everyone else. However, reassessing them for this new benefit does not make sense as a person with MND can only get worse, not better. The DWP has exempted those who are ‘terminally ill’ from the PIP assessment process. However, ‘terminal illness’ has arbitrarily been described as having a progressive disease and death from that disease can be reasonably expected within 6 months.

Charlotte
Charlotte has MND and lives in the East of Scotland with her husband David. David was an electrician until he had to stop work to become Charlotte’s full time carer. Charlotte relies on a powered wheelchair to get around and her voice is now affected too. Her health has deteriorated to such a degree that she receives higher rate care and mobility components of DLA which were awarded indefinitely. Even though Charlotte’s health will only get worse and she will only become more disabled, she will still have to undergo a full assessment for PIP when it replaces DLA this year.

MND Scotland has called on the DWP & UK Government to:

- automatically transfer, without assessment, those currently receiving higher rates of DLA mobility and care components to the enhanced rate of PIP. It is medically impossible for people with MND to improve so assessing them for PIP in these circumstances is illogical and an unnecessary cost to the taxpayer.
- extend the timescale under special rules that death from terminal illness can be reasonably expected from 6 to 12 months. Without this, reassessment for the enhanced rate of benefit would need to be incredibly regular (and therefore costly) to keep up with the rate of deterioration a person with MND will experience. If not, many people with MND will die before receiving the benefit they are entitled to.

MND Scotland Welfare Reform Campaign
With the forthcoming introduction of Universal Credit and resulting reduction of disability premiums, people with MND could also potentially lose up to £70 per week from their benefit entitlement.

Families dealing with a devastating terminal illness such as MND, with an average life expectancy from diagnosis of 14 months, should not be forced to go through the additional stress and anxiety caused by welfare reform cuts.
We have appealed to the UK Government to alleviate some of the burden for people with MND and their families. We have urged them to adopt a common sense approach by acknowledging that not only are people with MND unjustly suffering through welfare reform – assessing them for benefits they are clearly entitled to is a waste of taxpayers’ money.