

# Petitioner submission of 16 December 2022

## PE1854/O: Review the adult disability payment eligibility criteria for people with mobility needs

We were grateful to receive further correspondence from the Citizen Participation and Public Petitions committee, stating:

***“...The Committee was interested to receive more information about the specifics of conditions such as MS and any other information you consider to be relevant.”***

In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, physical and cognitive, and unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, debilitating fatigue and painful muscle spasms, among many other things. These symptoms can fluctuate from one day to the next. Some people with MS live with Relapsing Remitting MS, where relapses will occur and potentially have a devastating impact on their wellbeing, before they make a gradual recovery. Others live with Progressive MS where relapses generally do not occur but instead disability gradually worsens over time. Over 15,000 people in Scotland are currently living with MS, one of the highest rates of MS anywhere in the world.

Most people living with MS started to experience MS symptoms in their 20s and 30s, their prime working years. For people with MS the rate of employment is 41%, compared to 81% for non-disabled people.<sup>1</sup> As a result many in our community are reliant on support from social security to afford basic day to day items and meet general living costs.

General living costs are higher than they are for people who do not live with a disability. Life is more expensive if you are living with MS. On average the extra costs associated with living with MS total around £337 per month.<sup>2</sup> If you have MS your mobility may be limited so you may not move around as much and as such you will be colder, so you will need to have your heating on longer and at a higher temperature, leading to more expensive energy bills. You may have an electric wheelchair or other life

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<sup>1</sup> MS Society – Employment without Barriers

<sup>2</sup> MS Society – Reduced to Breaking Point

enhancing equipment that must be kept on charge, leading to higher electricity bills. You may have to follow a specialist diet leading to higher food bills. Adaptations to transport, treatments and therapies to cope with living with MS – all can be a significant financial burden that people who do not have a disability will not face.

All of this means that our MS community can be particularly vulnerable to rises in the cost of living and that their wellbeing can be dependent on having a social security system that meets their needs. As noted, paying for adaptations to transport can present a significant financial strain for our community. Qualifying for the Motability scheme and accessing a vehicle built to meet their needs can be the difference between them being able to have their independence and being confined to their home.

The MS Society 2018 Report “PIP: A step too far” found that 2% of respondents gave up work altogether because they lost out on the higher rate of mobility support and had to give up their Motability vehicle. This loss meant that they were unable to physically get to their workplace. It estimated that 611 people with MS will have had to give up work because of this between 2020 and 2022.<sup>3</sup> This is why we believe it is so important that the mobility criteria in Adult Disability Payment (ADP) is in line with the underlying principles of Social Security Scotland of dignity, fairness and respect. Our report contends that the 20-metre rule was the reason for many members of our community losing out on this support under Personal Independence Payment (PIP) and that since its introduction as part of PIP, the rule has acted as a barrier to people living with MS getting the support they need.

The latest figures from the Department of Work and Pensions (DWP) show that from across the UK of 1455 people living with MS who submitted a new claim for PIP between August and October 2022, only 52% of them received an award. Of those who were reassessed when moving from Disability Living Allowance (DLA) to PIP, 15% of those who were on the top rate of DLA saw their award decreased from the enhanced mobility rate to the standard mobility rate, while 10% lost their award entirely.<sup>4</sup> These stats in and of themselves are startling, but they belie a real human tragedy for 25% of those who under DLA had qualified for the enhanced rate of mobility support and a Motability vehicle, but who under the 20 metre eligibility criteria have now lost that support and with it their independence. Our research has found that since PIP began to replace DLA in 2013, one in three people with MS moving over to this benefit have

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<sup>3</sup> MS Society – PIP: A step too far

<sup>4</sup> DWP – Stat-Xplore

had their support downgraded, including one in ten who have lost support altogether.<sup>5</sup>

The MS community believe that because MS is a fluctuating condition, where the severity of symptoms can vary from day to day that the “20 metre rule” is particularly discriminatory towards them. One day a person with MS may be capable of walking 20 metres with limited difficulty, but they may have to spend the next day or even week in bed recuperating from it such is the severity of fatigue many will experience. Nor does the rule take into account what a disabled person who can walk this distance is supposed to do if shops or public transport are further away than 20 metres, which they almost certainly will be. The number of people with MS having their awards stopped or downgraded should not be at the rate we have seen under the 20 metre rule, as MS is a lifelong progressive condition where an individual’s needs are only ever likely to increase.

Furthermore in “The Cost of the PIP 20 metre rule” report, we found those who had their mobility support reduced or removed altogether had been forced to increase their use of GP services, and reduce spending on food and therapies. The report concluded that the rule increased, rather than reduced, the cost to government due to additional costs to the NHS and a rise in those claiming other income support. Demonstrating that the 20 metre rule is also a financial drain on services.<sup>6</sup>

Opposition to the 20 metre rule is widespread among civil society. Many bodies including the Health and Social Care ALLIANCE, Parkinson’s UK Scotland and the Neurological Alliance of Scotland have gave evidence to the committee in support of removing the 20 metre rule from Adult Disability Payment. So too have Citizens Advice Scotland (CAS), who in a survey in 2021 found that a majority of Bureaux advisers working to help people with disabilities navigate the social security system agreed that the 20 metre rule should be extended to 50 metres.<sup>7</sup>

We are grateful for the Committee’s continued interest in our petition and hope they view the Scottish Government’s promised Consultation on mobility criteria, scheduled to begin in late January 2023 as an opportunity for them to help amplify the views of disabled people by gathering further evidence and making a submission to it.

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<sup>5</sup> MS Society – PIP: A step too far

<sup>6</sup> MS Society – Cost of the 20 metre rule

<sup>7</sup> CAS – ADP Consultation response, March 2021