



PIP: A step too far

The impact of the 20 metre
rule on people with MS

Laura Wetherly and Rony Erez
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Foreword



Life is more expensive if you have MS. Things like an adapted car, treatments and therapies, and higher gas and electricity bills are just some of the extra costs many people with MS face.

On average, people with neurological conditions like MS spend an extra £200 each week to cover expenses related to their condition.

This is why disability benefits like Personal Independence Payment (PIP) are so vital. When we launched our MS: Enough campaign in 2015, 83% of people we surveyed said that without disability benefits they wouldn't be able to maintain their independence.

For Hilary, disability benefits meant she could afford Pilates classes to help manage her symptoms. For Rachel, who isn't able to walk to her bus stop, they meant she could access a Motability car. But both Hilary and Rachel have faced cuts to their benefits, alongside thousands of others with MS.

Since PIP began to replace Disability Living Allowance (DLA) in 2013, one in three people with MS moving over to this new benefit have had their support downgraded, including one in ten who have lost support altogether. This is happening even though MS is a progressive condition where people's needs are only likely to increase.

Our analysis shows this loss of support is also having a significant knock-on effect on local services and communities, costing the NHS at least an additional £7.7 million in GP and A&E services each year.

For people with MS, the biggest area of loss is in the mobility component and this can be put down to PIP's 20 metre rule. If you can walk just one step over 20 metres, roughly the length of two double-decker buses, you won't qualify for the higher rate of mobility support.

This rule simply doesn't make sense. It was strongly opposed by charities, people with MS and medical professionals when it was first introduced, and we're still waiting for the Government to provide evidence to explain how it achieves the aim of targeting help at those who need it most.

The 20 metre rule isn't the only way PIP is failing people with MS. We're repeatedly hearing that the application and assessment process are actually bad for people's health. The very system that's meant to make things better is having a detrimental impact on mental and physical wellbeing, as evidenced in this report. We also know that the process still doesn't reflect the realities of living with MS, including its fluctuating and hidden symptoms.

Enough is enough. Too many people with MS are losing their independence. And for the first time this report will lay bare the devastating financial and social impact PIP is having. PIP needs to change – starting with the Government scrapping the 20 metre rule.

Genevieve Edwards
Director of External Affairs,
MS Society

About MS

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. 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, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 100,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

The progressive and fluctuating nature of MS presents particular challenges for the assessment of Personal Independence Payment (PIP).

What is PIP

Since 2013, Personal Independence Payment (PIP) has started to replace Disability Living Allowance (DLA). PIP is a disability benefit designed to help disabled people of working age manage the extra costs associated with their condition. PIP is not means tested and can be claimed regardless of employment status.

There are two components to the benefit – the mobility component is for help with getting around, and the daily living component is for help with things like getting dressed, eating or making decisions. These components replace the mobility and care components in DLA respectively. Each component can be paid at a standard or enhanced rate. The maximum weekly award is £141.10.

Eligibility for PIP is usually determined at an assessment, after which the Department for Work and Pensions decides whether a person will get the mobility or daily living component (or both) and the rate of the award. The Department will also determine the length of the award, and when an individual will need to be reassessed for PIP.

About the MS Society

The MS Society is the UK's largest charity for people living with MS. We're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them manage their symptoms.

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About this report

This report examines the experiences of people with MS who have been reassessed from DLA to PIP since 2013. The report and its recommendations draw from research commissioned by the MS Society from ICM and Landman Economics. This included the following elements:

- A representative online survey of people with MS conducted between January and February 2018 by ICMUnlimited (ICM). The survey received 1,234 responses.
- Further economic analysis by Landman Economics of the online responses of the 447 people who transitioned from DLA to PIP.
- 18 in-depth qualitative interviews conducted with people with MS who had been impacted by the change-over from DLA to PIP. Interviews were conducted by ICM.

- Interviews with expert stakeholders whose views are cited anonymously throughout this report.
- A roundtable discussion with multi-disciplinary healthcare professionals about the impact and appropriateness of the 20 metre rule.

This report lays bare the significant, and too often negative, impact that the change from DLA to PIP has had on people with MS, and is supported by the views of people with MS and those who care for them. Five years since the introduction of PIP, this is the first report that focuses primarily on the effect of this new benefit on people with MS.



Introduction

MS can make it very difficult for people to maintain independent lives and access their communities. Unpredictable symptoms that can affect every aspect of their lives can make everyday activities like shopping, socialising, spending time with family and even working difficult and sometimes impossible. We know that a person with a neurological condition like MS will spend on average nearly £200 per week on costs relating to their condition¹.

Financial support to cover these extra costs is crucial to many people with MS – helping them to overcome barriers to independence and help them to do the things many of us take for granted. Over 60,000² people with MS across the UK – almost two thirds of our community – currently receive some form of extra cost disability benefit. The research we conducted at the launch of the MS Enough campaign showed very clearly how important this support is to people: of the 1,780 people with MS we surveyed in 2015, 83% said that without the support of disability benefits they would be unable to maintain their current level of independence³.

Since the introduction of PIP in 2013, small continual changes have been made to try and improve the process for people with complex conditions like MS. We, along with other organisations have commented on training materials for assessors and provided background information to try and improve understanding. This resulted in changes to the process for Award Reviews, and claimant communications have been made clearer. But despite these efforts to improve

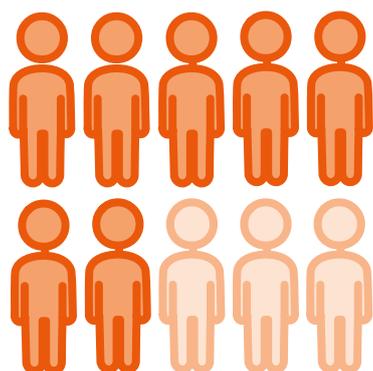
claimant experience, meaningful progress since 2015 has been slow and concentrated on the process rather than the unfair criteria.

Although they have a progressive condition, more and more people with MS have continued to lose money as the change from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) has continued to roll-out. Government figures show that between October 2013 and October 2016 – over 2,500 people with MS lost the highest rate of mobility support – almost a third (29%) of those who had the highest rate before they were reassessed. In addition, a quarter of those who had received the highest rate of DLA care support lost access to this during this same period⁴. We are concerned these people are facing substantially less support despite having a progressive condition and having previously proved the need for some level of support. It is now clear that more substantial change is needed to provide the appropriate support to people with MS and other disabled people.

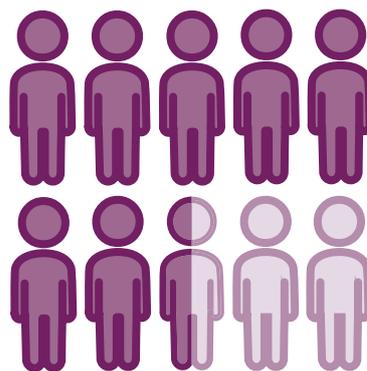
The assessment criteria for PIP have continued to fail to capture the true extent of the difficulties people face. Our research has found that the resulting loss of support is having significant negative impacts on people with MS and knock-on effects on communities and local services.

Having MS is enough – it shouldn't be made harder by a welfare system that doesn't make sense.

People with MS have lost the higher rate of support



29% on mobility



25% on care



Recommendations

- ▶ The Government should scrap the 20 metre measure for the highest rate of PIP mobility support. A review and design exercise should be carried out with disabled people, charities and healthcare professionals to design an agreed appropriate alternative. In the meantime the 50 metre threshold should be reinstated.
- ▶ The Department for Work and Pensions should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.
- ▶ The Department for Work and Pensions should amend the PIP assessment descriptors to embed the reliably, repeatedly, safely criteria and their definitions within the wording of each descriptor.
- ▶ The DWP should review the use of informal observations and their role in PIP assessments. While the review is ongoing, assessors should explain at the beginning of face to face assessments that claimants are subject to informal observations which may be included in the report to decision makers.
- ▶ The DWP should develop and implement a fairer process to exempt people with MS in receipt of the highest rate of award and whose condition is unlikely to change from repeated PIP reassessments and ensure award lengths are appropriate.
- ▶ The Department for Work and Pensions should introduce a requirement that all informal observations included in a PIP assessment should be supported by further evidence from individuals involved in a claimant's care.
- ▶ The Government should remove the 'aided' definition from the criteria for PIP assessment, in recognition that requiring a mobility aid suggests a significant restriction and impairment.

The problem: PIP is failing people with MS

The support provided by disability benefits can be instrumental in allowing people with MS to maintain independent lives. Since the original launch of the MS: Enough campaign in 2015 people have continued to tell us about the difference this support can make with coping with additional costs that can total more than £200 per week⁵. Of those who completed the survey, 94% who currently claim DLA or PIP have reported having extra expenditure due to living with MS:

Support around the home - an increase of 50% (average monthly spend of £104)



Treatment and therapies - an increase of 41% (average monthly spend of £114)



Essential daily travel - an increase of 35% (average monthly spend of £64)

Own vehicle expenses (e.g. petrol) - an increase of 41% (average monthly spend of £117)



Utility bills - an increase of 46% (average monthly spend of £83)

For those people who reported having access to the right financial support, the research was clear about the beneficial effect this had. Of those who had seen their awards increase on transition from DLA to PIP, 31% said it had positively impacted their financial security while over a fifth (21%) said it had a positive impact on their day to day life.

For some, the increased financial support from PIP has meant they are more able to access additional support to help manage their condition and improve their mobility: 8% of those who have had an increase in an award have started a new therapy or treatment, 16% have purchased new mobility support and 13% have been able to receive an adapted vehicle suitable to their needs from the Motability scheme⁶. Sizeable majorities who had more support from PIP also indicated they increased expenditure on other everyday expenses such as food (30%) and travel and transport (24%). This wide reaching change in spending habits indicates the central role that sources of financial support play in the day to day lives of people with MS.

'I can now afford the treatments, food and supplements and medication I need. It has given me peace of mind.'

'I have more money which helps with the household budget and allows me to socialise more.'

**‘it’s taken a lot of the strain out of having to pay for the gardening and cleaning and it means we do get to go out... go to different parts of the country and drive around’
‘I now receive a higher amount of monthly payment from PIP. This has enabled me to buy my Di Blasi mobility scooter and an all-terrain mobility buggy. It really does make a positive impact on my life. I am now able to pay for someone to cover the outside jobs that I once would have done - leaf clearance, wood logging, tree planting, hedging etc.’**

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The most recent available Government figures suggest that 34% of reassessments of people with MS resulted in an increased award, while 33% resulted in the same level of support. The remaining 33% of people with MS who have been reassessed had seen a decrease in their award, including 10% who had lost their support entirely⁷. That means that since PIP was introduced a great number of people with MS are seeing awards decrease on reassessment despite MS being a progressive condition.

These very concerning Government figures were strongly corroborated in our survey which found that of those who have been reassessed for PIP, 36% had seen a decrease in their award, including 7% who had lost their award entirely.

In February 2013, 94% of working age adults with MS receiving a DLA award got the enhanced rate of the mobility component⁸. By comparison, the latest statistics released for PIP at the time of publication

show that of working age PIP claimants with MS only 66% had received the equivalent mobility award⁹.

This significant reduction in the number of people accessing the highest rate of mobility support suggests that the criteria have significantly changed the level of mobility restriction claimants have to demonstrate to get support. In this report, we focus primarily on the impact of this reduction in support on people with MS. This is because more people with MS receive mobility support than the daily living element of PIP which is designed to help with other daily activities, and therefore more people are losing out on mobility support in the transition to PIP.

Increased need; reduced support

The statistics cited above do not reflect the true experience of people of MS who we know are likely to still have at least the same significant level of need. In many cases, their condition will have got worse since they were assessed for DLA. MS is a progressive condition, but even during periods of remission damage can be ongoing with resulting accumulating disability. For this reason we think it is very likely that for many, their needs will only have increased¹⁰.

This apparent disconnect between increased need but reduced support compounds frustration among people with MS. Survey respondents highlighted this in their responses:

‘I feel very upset that my allowance has hugely reduced when I was originally awarded DLA for life and I am way worse now than when I was originally assessed.’

‘When I lost the DLA I was very disappointed. I had received it for a number of years. Obviously I still have MS which is worse now than it was.’

‘My MS progressed significantly due to stress of job and divorce while on DLA. With change to PIP, I had to reapply and be assessed at my home due to difficulty using public transport and stairs. My assessor (who did not see me walk nor ask me to walk) claimed as I was able to walk 20-50m on a good day, I was not disabled enough to receive PIP mobility allowance. This was EXTREMELY upsetting and caused much anxiety.’

Health professionals agreed that this reduction doesn’t make sense given the prognosis of MS in the vast majority of cases.

‘Because MS is a progressive condition people don’t get better but this is implying that people are getting better which makes no sense at all. There’s no scientific basis for this... because as you’ve already been discussing there are lots of hidden costs so there is no scientific rationale or basis to it... and it’s negatively impacting [people with MS]’ – quote from a neurologist at expert roundtable

‘The PIP assessment is flawed, it’s not picking up the progression that people are suffering’ – quote from a neurologist at expert roundtable

MS is different for everyone. All types of the condition have an underlying progressive disease course. People with forms of the disease clinically categorised as either primary or secondary progressive MS are likely to see the most pronounced progression of disability over time. Currently, the DWP does not make available data on the breakdown of PIP claimants by MS diagnosis. However, from the survey conducted by ICM, we found that 40% of those who had a decrease in their award on reassessment from DLA to PIP identified as having a progressive form of MS. In addition, nearly two thirds (64%) of those who reported they had experienced a decrease in support had been diagnosed over 11 years ago.

Leaving those with the highest need behind

People with MS often experience problems with mobility, which affect many aspects of their day to day lives, from being able to shop for food to staying in work. PIP helps people with MS cope with these challenges. Despite the apparent need, reduction in support often negatively impacts on the ability of people with MS to continue to lead independent lives. Of those who have had a reduction in support following a reassessment to PIP, three quarters (74%) said it had a negative effect on their daily lives.

49% of people with primary and 23% of people with secondary progressive MS have seen a reduction in their PIP award. While it’s true that many with these types of MS have seen an increase in their award, the fact remains that too many people with MS are losing vital support.

It is alarming that a high proportion of those who experienced a reduction in support have progressive forms of MS. For this group, it is expected that symptoms will worsen over time, meaning that a reduction in level of support is excluding those with higher need from appropriate financial support to help them cope with often debilitating symptoms. While the stated purpose of PIP was to support those most in need, it seems that it fails to do so for too many people with MS.



Caryl, 65

Caryl lives with her husband in Carmarthenshire. She has four grown children who have moved out of the family home. For the last 20 years Caryl has had relapsing remitting MS, but six months ago she was told she now has secondary progressive MS. Her day to day life is affected by fatigue, problems with balance, and worsening eye sight. Her MS also makes her forgetful and she experiences brain fog. Because of this, Caryl needs help with activities such as showering, and has to drive everywhere because she cannot walk for very long without resting.

Under DLA, Caryl received the higher rate for both care and mobility, and used her payment towards purchasing an automatic car, because the left side of her body is weak. When she was reassessed to PIP in 2016 her award rate was reduced for both components, which significantly affected the couple's life. Specifically, the award rate for mobility was reduced because the assessor said Caryl can walk more than 20 metres.

'The higher payments made life easier, they contribute to finances, we've got a pretty hefty mortgage on this house, so it contributed to the weekly outgoings. We've had to cut back on everything really. Food costs, drink costs, general maintenance. One thing I've had to cut back on is heating during the winter months and you know I'm cold. I'm one of those people with MS who feel the cold and love the heat. I think it's made the MS worse, made me slower and less able to move around.'

'We've cut back on social activities. We go once a month to the comedy club, and before we used to go out for a meal before the comedy, but now we can no longer afford to do that. Our friends still meet for the meal beforehand and it's made me feel singled out, more than having MS in the first place.'

'To move 20 metres is nothing. The bus stop is further than that and I can't walk it. I have to drive everywhere which is an extra cost.'

'I expected it to stay the same, this new silly rule has impacted quite significantly on us'

Making a difficult situation worse

Living with MS can be hard enough. Coping with MS can often be challenging – having to give up work, relying on the care and support of family and friends, and dealing with the loss of mobility and the isolation that can sometimes cause – these are all issues that can negatively affect the emotional and mental wellbeing of people with MS. Even relationships with loved ones strain because of having MS.

‘I try to stay positive but I hate that I am losing my mind and my body. I live in the darkness because I can’t even go outside’

‘... I used to be so sharp, and some of the things I struggle to do now make me feel so stupid. It’s devastating for me. I struggle to do the simplest things’.

PIP should be there to help people with MS live independent lives, to make their situation better and to help cope with the challenges of having MS. It can do that, for example, by helping to pay for the support a person living with MS needs at home such as cleaning and gardening, or by helping to pay for transport costs so that people are able to socialise or volunteer. It can also help to pay for treatments, therapies and counselling that can all help to increase mental and physical wellbeing. Conversely, lack of support can make a difficult situation worse, as people with MS lack the ability to lead independent lives and manage their condition well.

People with MS say moving from DLA to PIP had a negative effect



78%
on their financial security



74%
on their day to day life



65%
on their mobility

The impact: Reduced support negatively affects everyone

Across the research the impact of the reductions in support being experienced by people with MS was consistently found to be very negative. 78% of the respondents to the survey who had been reassessed from DLA to PIP and had received a reduced award said it had negatively impacted their financial security while 74% said it had negatively impacted their day to day life and 65% their mobility.

The meaningfulness of this reduction and its impact comes through even more clearly from what survey respondents said this meant for their spending habits and activities. Not only had many reduced spending on hobbies and leisure or socialising activities (43%), but essential spending had also reduced for many. Over a third (39%) said they were spending less on food and over one fifth (22%) had reduced spending on utilities such as gas/electric bills.

Impact on mobility

Many people with MS begin to experience symptoms that affect their mobility as the condition progresses. This includes loss of movement in the limbs, including legs, as well as pain and fatigue when walking. Each person experiences the symptoms of MS differently, and these can also fluctuate from day to day or even hour to hour. Many people with MS find it difficult to walk without the assistance of aids, and many rely on scooters and cars to help them get around and go about their daily lives – going to the shops or medical appointments, visiting friends and going to work.

The Motability scheme is there to help disabled people who have reduced mobility lease a car or scooter, using PIP, but only people who receive the higher rate of award are eligible for the scheme. The scheme is important because it provides not just the vehicle but also any adaptations the driver requires.

Having access to an adapted car can make all the difference between living an independent life, to being isolated from family, friends and the ability to work. At the time PIP was introduced, the MS Society and other organisations warned that the 20 metre rule could lead to people 'being trapped

in their own homes'¹¹. This now seems to be the case for some people with MS who have experienced a reduction in support.

'Reduced money means that I am now confined to the house as I am about to hand my car back as they say I don't need it. Unable to manage public transport. Worrying as waiting to hear from tribunal. Not sleeping properly as worried so this has impact on my mobility as when I am tired I do not walk as well.'

'As I lost my mobility car, I am now worse off financially also this stops me visiting friends and family making me more depressed as I am more housebound after work'

For drivers, receiving the higher rate of PIP also gives automatic eligibility for disabled parking through the Blue Badge scheme, which is operated by local authorities. The Blue Badge enables people with MS to park close to their destination, helping reduce the amount of walking necessary. Losing the higher rate award of mobility then means losing the Blue Badge, and having to go through a separate assessment by the local authority in order to keep this benefit, but the outcome of the assessment isn't always successful. Losing the Blue Badge can mean that even if a person buys their own car, they are not able to park close to shops or doctor surgeries.

The mobility PIP payment also helps those who do not drive, or do not own a car. It helps, for example, to pay for taxis for people who cannot use public transport.

The loss of this support, whether in the form of leasing a car, or the ability to pay for other forms of accessible transport, can mean losing the ability to work, care for other members of the family or continue to socialise. For a person with MS this can mean losing the ability to live independently and sometimes it can mean living in isolation from society. It can also mean not being able to manage their MS, as they are unable to get to medical appointments or to other treatments and therapies that help manage symptoms.

Travelling on public transport when you have MS

Many people with MS start seeing reduced mobility as their condition progresses. Over time, the ability to walk becomes more difficult, for many even for short distances. This, in turn, impacts the ability to use public transport.

The number of journeys by bus in the UK far exceeds any other form of public transport – in 2016 there were 4.9 billion passenger journeys on local bus services, which is 5% of all passenger journeys in the country. This compares with 2% of passenger transport journeys by rail¹².

It is no wonder then, that the most common comment relating to mobility we received during our research was about how far away an individual's nearest bus stop is. For some people in the UK, like Rachel who is featured in our report, the nearest bus stop is a mile away! Walking such a distance just to get to the bus stop when your mobility is severely impaired simply isn't an option.

Even in a city like London which has the most extensive bus network in the country, transport guidelines for the city state that the ideal distance for bus stops from homes should be about four or five minutes' walk, which is around 400 metres at an average walking speed¹³. This means that for people with MS who can walk 20 metres, even the nearest bus stop would be at a distance 20 times further than they can walk. So what might seem like an easy stroll to the nearest bus stop for an average person, might as well be miles away for someone with MS.

But getting to the bus stop is just the first hurdle. What if the nearest bus doesn't go to your final destination? Or if you have to change and take a train? Can you manage the stairs if there's no lift? If you have to take another bus, or walk again to reach your destination, how fatigued will you be?

Only people who cannot walk 20 metres are eligible for the highest rate of support for PIP. 20 metres is equivalent to around the length of two double-decker buses, so if you can walk just over that length, you won't get the highest rate of support, and you won't be eligible for the Motability scheme. But even if you can walk 20 metres but not much more, where does that get you in the real world of public transport in the UK? The answer is, probably not very far.





Rachel, 50

Rachel was diagnosed with relapsing remitting MS in 2002, and with secondary progressive MS in 2012. She is 50 and lives with her husband and son in West Yorkshire. Rachel works part-time as a librarian. Rachel lives in a rural area, so in order to do things such as shopping she relies on her adapted car. Her home is also fitted with adaptations such as rails. Her mobility is severely impacted so she uses Zimmer frames, a walking stick and a mobility scooter to get around both inside and outside the house. Rachel is frequently not able to cook, so she uses frozen food for herself and her son.

Under DLA Rachel received the lower rate for care, and the higher rate for mobility. In 2016 she was assessed for PIP at home, and her mobility payment was completely taken away. Rachel lost her Motability car as a result. The loss of the support meant that Rachel had to use her pension savings to lease a car and pay for the required adaptations. It also meant cutting down on socialising and eating out.

Rachel asked the Department for Work and Pensions to reconsider, but the decision was upheld. With the help of a legal advisor Rachel appealed to the tribunal, but in April 2018, a month before the tribunal date, the Department reinstated her award.

“In order for me to get out of this house, if I was using public transport I would have to walk a mile to catch a bus”

‘I think I am a really positive person. I know what I have and that it is debilitating disease, but I take pride in what I am able to do. So yes – I drive unaided from my house to my Dad’s who is a 100 miles away door to door, and of course I put this on the form and I was penalised for that. What they wanted to read was – no you can’t do that. That is quite a different mind set from what I have got, that’s not positive’

‘On the initial DLA form I don’t think they were particularly different to (PIP) but the approach to the final funding was very, very different. This time round you are not getting it until you can give me a damn good reason. Before it was – you have MS ok will give you some money’

‘The processes the assessor went through didn’t take into account the difficulty of the places around me or the ramp to the front door’

PIP is damaging the health of people with MS

The impact of reduced support for PIP does not only mean people with MS cannot cover extra and essential costs associated with their condition or that it leaves them struggling to maintain their independence. Our research suggests that PIP is also significantly impacting on the physical health and wellbeing of people with MS. In some cases, our evidence suggests that PIP is causing people's MS to deteriorate or relapse.

Amongst those who had received a reduced award on reassessment from DLA to PIP, a significant majority (65%) said that the transition had a negative impact on the state of their MS and over half (57%) said it had a negative impact on their physical health. This may in part be explained by the reduced financial support available for people to cover costs associated with their condition. If, as some respondents suggested, people are struggling to pay for essentials it is not necessarily surprising that their health has been impacted.

However, respondents to the survey also told us that reduced awards for PIP impacted spending on care and treatments- suggesting a direct relationship between reduced support and negative impact on health. 30% of those whose PIP had decreased reported spending less on therapies and treatments, while 8% said they had reduced or stopped paid care as a result.

'[PIP] has put massive financial strain on myself and caused me much stress that I relapsed.as PIP assessors don't believe anything you tell them and you have to appeal everything to get what you already had on DLA – it's a total disgrace.'

'The whole process which for me lasted 18 months changing from DLA to PIP. It was extremely distressing and draining on my emotional and physical health. It makes you feel very uncertain and vulnerable and this has impacted me a lot. I have lost my Motability car and now have to privately lease one using my

care money pip as I'm unable to wait for public transport. As I'm now using my care allowance to pay for my car or my legs as I like to call it I am unable to afford the supplements and alternative treatments I was previously using my care allowance for which has obviously impacted my health. The whole process is so unfair and it's disgusting how the sick and disabled have been targeted. '

'The overall effect has been negative mainly. It has highlighted the disability and made it more difficult to achieve some of the things I used to be able to do. I no longer go regularly to the MS Society exercise class at the local YMCA due to cost of membership and taxi to get me there... Reduction in benefit was a bit of a body blow as I had not realised how much I depended on the finance to access things like physio and keeping my house clean and tidy. I live in a muddle and mess is not good or helpful to the wellbeing of the mental state of an MS sufferer.'

'Less money to spend on my care'

Applying for, and accessing disability benefits, is hugely challenging. Across the board, the experience of applying for and being assessed for PIP has had lasting negative impacts for people with MS. While these are understandably most pronounced among people with MS who have ended up with less support, negative consequences are not isolated to this group. Shockingly, people with MS who have managed to receive higher support on reassessment also report that the transition from DLA to PIP has had negative impacts across a number of areas of their lives, including physical and mental health. Over a third (35%) of those who had received an increase in an award, said that it had a negative impact on their emotional wellbeing, a third (33%) reported a negative impact on the state of their MS and over a quarter (27%) on their physical health.

This suggests that the design of PIP and the application process is inappropriate and harmful

for people with MS. The in-depth qualitative interviews conducted by ICM to explore further the findings of the survey give more detail to this interpretation. ICM deliberately selected interviewees to represent a range of different experiences and outcomes of the PIP process (both positive and negative), yet they found that with the exception of 2-3 participants, all spontaneously used words such as ‘stressful’, ‘worrying’, ‘uncertain’ and ‘horrible’ to describe the experience.

Some interview participants reported a worsening of their MS symptoms whilst going through the PIP assessment.

‘Well to be honest, (my MS) actually took a nosedive around the time that I had to do the PIP assessment... I don’t know whether MS is stress related, but it certainly seems to exacerbate it. The pressure of doing PIP,

feeling like I was putting it on when I knew that I wasn’t’

We asked all respondents to our survey, including those who received an increased award, whether the impact of moving from DLA to PIP was a positive or negative one. The analysis of the data, carried out by Howard Reed at Landman Economics, suggests that the overall impact of moving to PIP is negative across all aspects of life. The largest overall negative scores are for physical and mental health, emotional wellbeing, the state of MS and physical health. The overall impact is also negative for financial security, relationships with family and friends, mobility and day-to-day life. The table below provides a detailed account of the overall negative impact on aspects of daily life on people with MS who have transitioned from DLA to PIP.

The negative and positive impact of transition from DLA to PIP on various aspects of life

Impact of transition from DLA to PIP on aspect of life:	% of sample reporting:			Positive-negative balance
	Positive impact	Negative impact	No impact	
Day-to-day life	13	49	35	-36
Mobility	9	42	45	-33
Emotional well-being	8	59	28	-51
Social life	6	37	52	-31
Ability to work	3	19	72	-16
Financial security	17	52	24	-35
Relationships with family or friends	4	25	64	-21
Memory and thinking	3	32	59	-29
Physical health	5	44	48	-39
State of your MS condition	4	51	39	-47

Nina, 50

Nina, who lives in Suffolk, has relapsing remitting MS. She was diagnosed in 1998. Nina needs to go to the swimming pool at her gym and have regular massages in order to manage her condition and maintain her flexibility and walking. Nina uses two walking sticks because her MS causes her to have poor balance and coordination.

In 2016 Nina was reassessed to PIP, and lost all her award. This was after receiving DLA for 10 years at the higher rate for mobility and the lowest rate for care. Nina lost her eligibility for the Motability scheme, but luckily she was able to purchase the car.

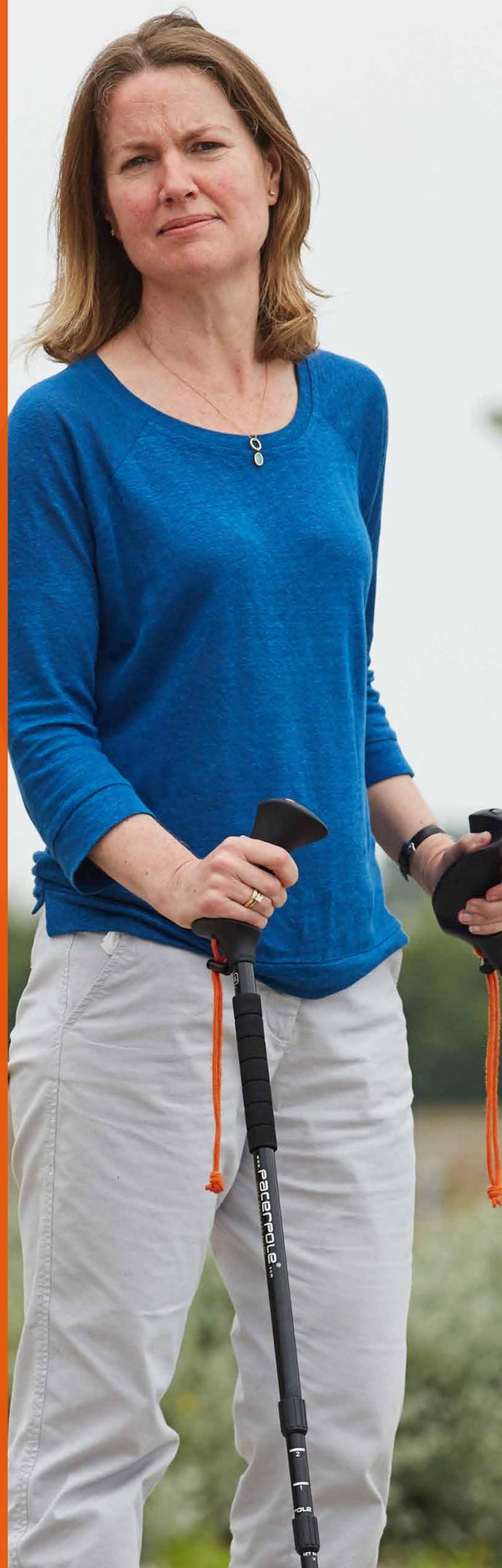
Nina continues to pay for her gym membership from her husband's income, but is no longer able to afford paying for massage treatments. This has a detrimental effect on her wellbeing and her ability to manage her symptoms.

'Well, we had to buy the car that I had which was only, at that stage, a year old. Then we had the £2,000 contribution towards it from Motability. I mean, in theory, 'Thanks very much.' I've got a slightly cheaper car. The thing that I was really worried about was that through having the car, I automatically got the blue badge. I was thinking, 'Oh my goodness, my life would be over if I didn't have my blue badge.'

'If you're the kind of person that doesn't like thinking of yourself in your worst possible day which is what you're required to do, and if you don't like to view yourself as a victim that can't do things, that you focus on what you can do, you just don't qualify, you just don't fit into the category that they feel is deserving of an award.'

'Living with MS is challenging enough as it is without having benefits withdrawn and not to be deemed to be worthy of them when you really could do with the help.'

'That was my problem with the PIP form. Although I have a lot of difficulty doing stuff, I try and find ways to work around it so that I can still do as much as I can as often as I can. But that disqualifies you for any assistance. At the time I would try and walk the dog every day. On a good day I could walk a mile and on other days I couldn't get out of the door. That meant I wasn't eligible because I showed that I could do it. The fact that I could do it and then I'd have to come back and sit down for the next two hours and I wouldn't then be able to go and make myself a drink because I would be too tired, there is no place to express that in the confines of the PIP application form.'



When people lose their independence, we all lose out

This sizable negative impact of PIP on people with MS has significant repercussions on those around them and the wider communities where they live. From decreased ability to participate in social and leisure activities, to impacts on volunteering and employment as well as increased dependence on family and friends, the impact is much bigger than that just felt by the individual.

While half of those who had been reassessed and received a reduced award said it had no impact on relationships with family and friends, a sizeable minority (38%) say it has had a negative impact, while over half (55%) say it has had a negative impact on their social life. This is consistent in the answers given to the question about what action they have taken due to a decrease in award, with over half (52%) saying they have had to reduce or stop leisure/social activities.

Almost one in ten (9%) say they have had to reduce or stop volunteering. Unpaid formal volunteering is incredibly important for the UK economy. The Office for National Statistics calculated that in 2015, an estimated 2 billion volunteer hours were worth

£23 billion to the economy¹⁴. Volunteering is also important for people with MS as a way to keep some routine once work is no longer possible. It is also important as a way to stay active outside the home, meet other people and for a sense of self-esteem derived from continuing to contribute to society.

Impact on employment

People with MS feel that their condition has a significant impact on their ability to work. Only 30% of the people with MS we surveyed are in work, with only half of those in full time work. This is an even lower level of employment than the one captured by the MS Society's My MS My Needs 2 survey, in which 35% of respondents said they were working either full-time or part-time¹⁵.

Direct impacts on the employment of people with MS is small but noticeable. 13% of those who are in work and had received a reduced award said they had reduced working hours. For others, a reduction in financial support has meant they have had to keep working or maintain hours inappropriately. ICM found that some people feel pressured to stay in work because they cannot afford to cover living costs now support had been reduced. In some cases, this had been detrimental to their health.

People who lost support had to reduce their spending

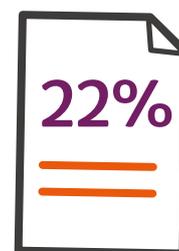


spend less on leisure and socialising activities



39%

spend less on food



spend less on utilities such as gas/electric bills.

'I had DLA for life. PIP meant award was withdrawn. I had to have to have a loan for a car to get to work but could not afford an automatic car. I took PIP decision to appeal. it took 1 year of my life to have mobility enhanced rate awarded at appeal. Very stressful year. I need to work and want to work - the PIP allows me to stay in work. Without a car through the mobility scheme my life was much harder as I did not have a blue badge. I cannot walk to offices without being able to park in disabled bays. The year it took cost me around £4000 and a great deal of unnecessary stress'

'I relied on it to help with costs for getting to work or attending social events i.e getting taxis. Helped towards my monthly financial income which was not huge in the first instance. The loss of it per month was a loss and a negative impact. Made me think before undertaking travelling any distance as this was my travel fund.'

PIP can support people to stay in employment by helping to pay for transport costs to work, or for additional help around the home – working can induce fatigue which leaves little energy left for doing the house work.

However, working is not appropriate for many people with MS. For people who leave work, PIP helps cover costs which cannot be paid for from wages. Consequently, the loss of PIP means that people who would not otherwise be working due to the symptoms of their MS, continue to work. This can negatively affect their condition and mean that people are less able to manage their MS and see their symptoms worsen.

'I'm having to do twelve-hour days and nights to get the money that I'm on now. It's difficult

to go and get an eight-hour job somewhere and probably get the same amount of money. I would have had to take a drop in pay. That would have given me the security, the knowledge to say, 'Yes, I can afford to take a drop in pay because I'm getting DLA, the PIP' Now, I can't because I'm not getting that so it doesn't give me that back-up, that bit of security to do that. The confidence to do that. I've been struggling on doing the job that I'm doing. Alright, I'm getting a little bit of an easier job but I'm still doing the silly hours that's tiring me out and not helping my fatigue...'

The need to continue working due to a reduction in PIP is borne out by the findings of our survey, which shows that people who received a reduced payment are significantly more likely to be in work – 29% are more likely to be working at least part time compared to 16% of those whose award increased. While some of the people still in work are likely to be those with symptoms that are manageable enough to stay in employment, this can also be due to the drop in support that means they need to continue to stay in work because they cannot afford to live without the income.

Impact on friends and family

The increase in financial insecurity and reduced independence has a knock-on effect on family and friends, who from our research, are increasingly having to pick up the slack for reduced access to support and care, as well as reduced financial resources and increased insecurity. Within the interviews of those who had received a reduced award, respondents reported their partners feeling additional pressure to stay in work as the main or sole breadwinner. This can be a particular pressure where their partner is also already providing informal care.

‘(My husband) is a person working, he is not my carer... I suppose it added to his feeling of, ‘oh right, I’m responsible for bringing in the money.’

The survey suggests that despite this increased perception of pressure to remain in employment due to reduced financial support, in a significant number of cases reduced PIP actually means family or partners are working less in order to provide more support. 13% of respondents who had a reduction in financial support from PIP said that family or friends had reduced their working hours to support them and an additional 6% said that family or friends had stopped working altogether to be their main carer.

‘My wife cannot work more than 1 hour and half a day because she needs to look after me the rest of the time. She leaves everything I need on the table and then she comes back and check on me. So, living off her wage and not having any extra money has been very difficult. My wife only just found out about the carer allowance too’

In a significant number of cases, family and friends are providing financial support. 27% of those who had a reduction in support reported that family or friends had lent them a sum of money to help them with their finances. It is deeply disturbing that for some families this is resulting in increased debt in order to provide this support and make up the shortfall in financial support. Furthermore, 6% of people with MS who had received less support said family or friends had taken out a loan to help them with their finances, meaning that financial strain is placed not just on the person with MS but on their loved ones as well.

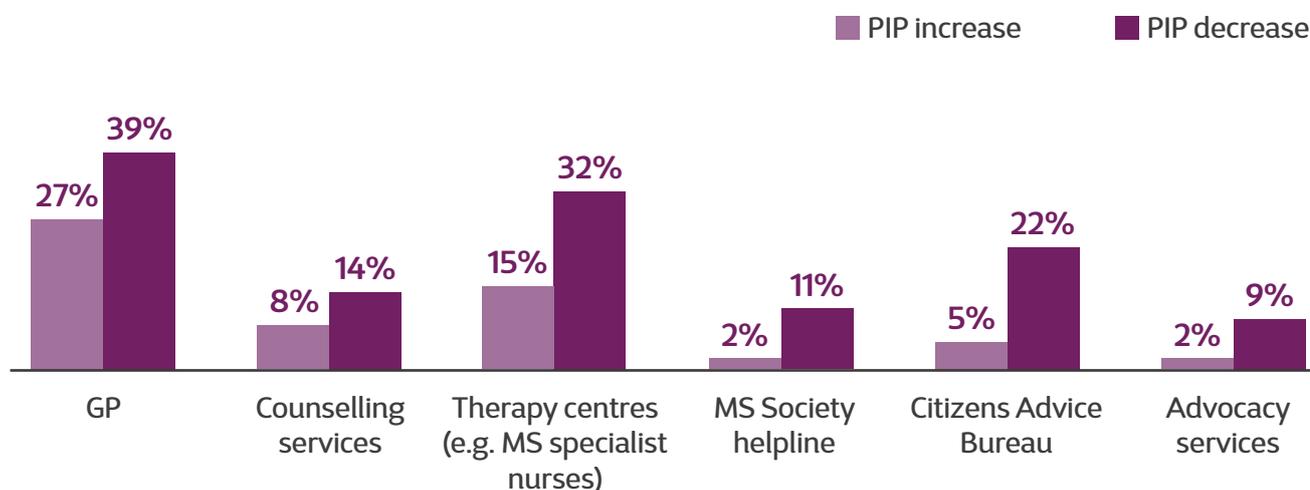
Impact on services

Through the course of this research it has become clear that the damage is not limited to the MS community. The inappropriate nature of PIP for MS and the restrictions in financial support this is leading to are beginning to have a knock-on impact on other services.

‘You can get advice from the Citizens Advice and they will tell you how to fill it in. Again, it’s almost like you have to end up looking like you’ve fulfilled all the criteria. If you don’t, well then it’s just thrown out. Even though you really could do with some help’

This research begins to further substantiate concerns that the MS Society laid out at the time of the original PIP proposals about the impact they would have¹⁶. ICM asked people with MS who had received a change in award on reassessment whether this had impacted their use of services. Across a number of services, people with MS said their use has gone up as a result of the transition to PIP. The most pronounced was GP services which had a reported net increase of 39% among people with MS who had a decreased award, followed by therapy centres (32%), Citizens’ Advice Bureau (CAB) (22%), counselling services (14%) and the MS Society helpline (11%). This suggests that PIP is putting additional strain on other services and may be causing increased costs across other areas of Government spending, as well as the third sector. Reductions in support provided by PIP is costing services more in the long term.

The increase in use of other services for people with increased and decreased PIP award



Responses from people who received a PIP award at a decreased and increased rate to DLA to the question: 'For which of the following additional services, if any, has your use increased or decreased following the changes in your PIP award?'

If these results were replicated across the national population of people with MS the impacts would be very significant. Our helpline data demonstrates the role of benefit changes as a driver for service demand and the potential cost incurred. As mentioned above, 11% of those who had a decrease in their award, as well as 2% of those who had an increase in their award reported increased use of the helpline service, where each call taken by the helpline costs £30. Based on the latest figures of people with MS of working age in receipt of DLA, who are waiting to be reassessed for PIP (23,668 as of November 2017)¹⁷, we anticipate that by the time PIP is fully rolled out, the increased costs to the MS Society helpline will be at least £92,305.

It is important to note that calls regarding benefits/ financial difficulty were the third largest reason for enquires to our MS Helpline in 2018. The highest number of enquiries to the helpline are from people with MS seeking grants or financial help.

The substantial demonstrated increase in use of GP services may be linked to the decreased ability of people with MS who have had a decrease in their award to manage their MS and general wellbeing, leading to a need for healthcare interventions. For the NHS, this means a large increase in spending on primary care – our research suggests that the NHS would spend just over an additional £1.8 million pounds per year on GP services for people with MS who have been reassessed from DLA to PIP¹⁸.

Additionally, our research shows that 9% of respondents have used for the first time, slightly increased or significantly increased their use of Accidents and Emergency hospital service. An increase of use on this scale by people with MS who have been reassessed from DLA translates to an increase of expenditure for the NHS of £5.9 million per year¹⁹.

This means that the increase in costs to the NHS per year is at least £7.7 million when only considering these two services. People with MS who receive a reduced award may also increase their number of visits to their MS nurse, as well as seek out counselling and therapy services, increasing the extra expenditure for the NHS even further.²⁰

This staggering increase in the amount spent by the NHS points to a possible transfer of costs by the state from benefits to healthcare spending, and also to deteriorating health and the loss of the ability to maintain health and wellbeing as result of reductions in PIP awards for people with MS.

Healthcare professionals who contributed to the stakeholder interviews and the roundtable as part of this research echo this concern about the impact of PIP on wider services. Anecdotally, they told us about their experience of the change in demand relating to PIP.

A consultant neurologist told us that health and social care had seen added pressure, picking up the slack from PIP changes. She gave us the example of people who become isolated will become depressed and then contact more GPs and centres, with related issues. In her experience, individuals are now asking for MS Therapy centres to provide additional services that PIP would have otherwise paid for.

In addition, PIP is leading to increased demand for services because often when there is changes to disability benefits individuals go straight to their clinician for advice, such as writing reports or helping with appeals. This then burdens health assistants. – stakeholder interview with a consultant neurologist

A MS specialist nurse currently working in a centre with a caseload of 1600 people with MS said that since the changes in PIP eligibility she has noticed a significantly increased workload, not only helping clients with applications but also of those individuals seeking advice form MS therapy centres regarding appealing the decision of their awards. This has been particularly concentrated towards individuals who have lost their enhanced rate of the mobility component.

She also flagged that socioeconomic impacts may lead to a reduction in the level and quality of care which they previously received, and this will be falling upon family members who may have to reduce their working hours – stakeholder interview with an MS specialist nurse.



NHS spending is higher because of PIP

£1.8 million
on GP services

£5.9 million on

A&E

In the course of the MS Society's work on PIP since it was introduced in 2013, we have continued to hear healthcare professionals tell us that their workload has been changed by the impact of PIP on people with MS. This research suggests this may be a combination of several factors. Firstly, people with MS are seeking help and support to provide evidence and through appeals processes.

However, from the results of our survey and discussion with people of the MS, it is clear that the direct impact of reduced support is also contributing to this growing pressure. As laid out in this report, PIP is negatively impacting both the physical and mental health of many people with MS – so it's sensible to suggest this may be leading to increased need for health support. In addition to evidence of changing their use of services, responses to ICM's survey suggests that reductions in awards are also leaving many people with MS unable to maintain the care and treatments they would have been managing or

funding themselves – potentially meaning they are then seeking replacement support from NHS services. 20% of those who had a decreased award had reduced treatments or therapies, and 14% had stopped them altogether. At the same time, 4% had reduced the number of paid caring hours and 3% had stopped receiving paid care altogether.

'It makes you feel very uncertain and vulnerable and this has impacted me a lot. I have lost my Motability car and now have to privately lease one using my care money PIP as I'm unable to wait for public transport. As I'm now using my care allowance to pay for my car or my legs as I like to call it I am unable to afford the supplements and alternative treatments I was previously using my care allowance for which has obviously impacted my health. The whole process is so unfair and it's disgusting how the sick and disabled have been targeted.'



Salah, 41

Salah was diagnosed with MS in Spain in 2002. He moved to Cardiff in 2008, to be nearer the support provided by his two sisters who live in the city. A former security guard, he stopped working in 2012 due to his secondary progressive MS, which means he is unable to walk very much and needs a walking stick. Salah also has pain in his legs, and is sensitive to light and sound which cause him headaches, severely restricting his ability to leave his house.

Maria, Salah's wife, is his carer. As he cannot do many things like eat or wash, Maria has to help him, and is therefore only able to work 1.5 hours per day. When Salah was assessed for PIP, he lost his entire award, both for care and for mobility.

As Salah cannot walk very well, he has to spend money on taxis to get around, as the bus stop is too far from his home. The reduction in the PIP payment means that the couple and their children now have to cut back on heating over the winter and reduce the amount of food they buy. The process of applying and then going to tribunal, helped by the MS Society and Citizens' Advice, has greatly affected the whole family, causing stress and confusion.

“My wife cannot work more than 1 hour and a half a day because she needs to look after me the rest of the time. She leaves everything I need on the table and then she comes back and checks on me. So, living off her wage and not having any extra money has been very difficult. My wife only just found out about the carer's allowance too”

‘We had to cut back on heating and electricity. The house isn't very well insulated, so it has been very cold. We also had to cut back on the cost of food. We don't eat out of the house ever anyway, so this just meant cutting back on food for the family.’

‘When I think about the decrease I feel so stressed and depressed. They didn't consider what I said [about my condition], they even put the opposite. The evidence that they have is only what they wrote’

‘I want to go and give them [the assessors] a booklet about MS, they had no idea what it was’

‘I try to stay positive but I hate that I am losing my mind and my body. I live in the darkness because I can't even go outside’

The cause: The senseless criteria

The devastating impact of PIP on people with MS has continued despite ongoing calls and efforts by the MS Society and other disability organisations to make improvements to the assessments and the process. Since 2013, five independent reviews have been carried out and responded to by Government as well as scrutiny from parliamentarians, including the recent Work and Pensions Select Committee inquiry into PIP and ESA assessments²¹. From these reviews, a number of changes have been implemented. These have included the production of videos explaining the PIP claiming process, provision of information to healthcare professionals on providing supporting evidence, and improved communication with claimants. The Department is also now looking at allowing all PIP assessments to be recorded, as is already the case for the Work Capability Assessment.

One of the assessment providers has also changed the format of the assessment, so that impact on daily functions is assessed first, before discussing any medical history. This is claimed to produce better quality reports for decision makers, as claimants and assessors are able to have a better discussion around the impact to daily living and mobility, rather than focusing on the condition and seeing the assessment as medical in nature.

Yet, even with the improvements that have been made so far, the rate of reduced and refused awards for people with MS has not improved. In December 2016, Government figures showed that 33% of people with MS who had been reassessed had received a reduced award, including 10% who had lost their award entirely²². A year later, as of December 2017, this figure remained static.²³

In most cases, these decisions are not revised by DWP decision-makers on review and reconsideration by the Department. As of January 2018, 78% of decisions following a reassessment from DLA which disabled claimants asked to be looked at again were confirmed and upheld. For claimants new to PIP, the figure is even higher –

84% of decisions for new claimants were upheld by the Department following a request to reconsider.

However, the significant number of people with MS with ongoing and often worsening need who continue to lose support point to deeper issues with the design of the assessment. People with MS feel strongly that PIP is not appropriately designed for the complexity of their condition.

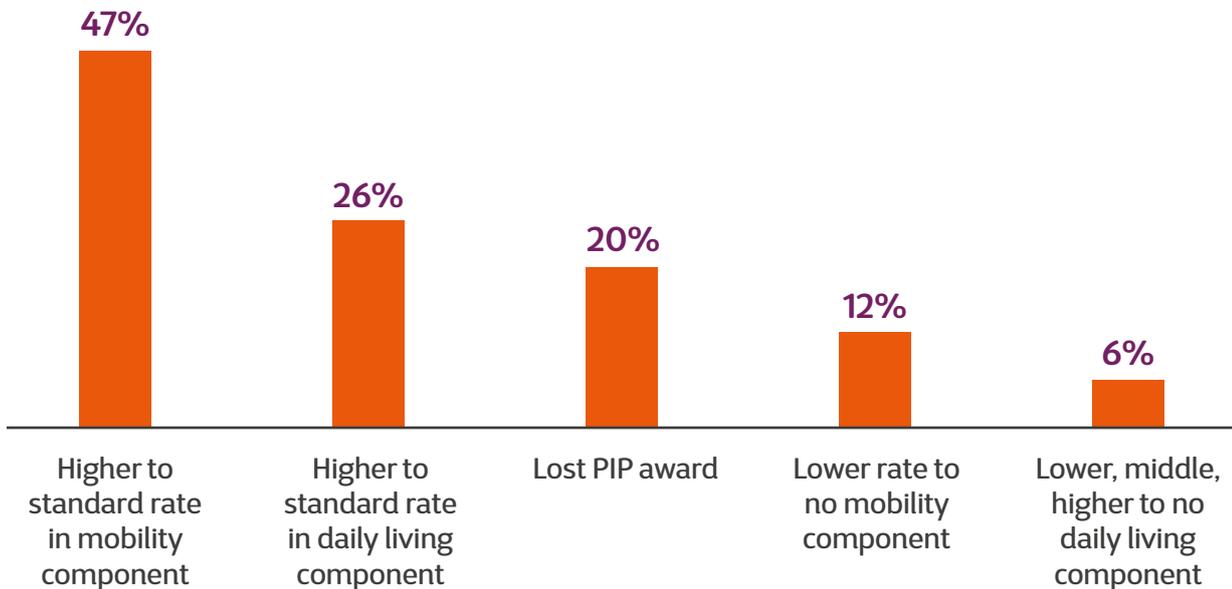
‘I think the application is clearly biased to people who have absolutely no mobility and in 100% care. So, everything is on a scale, the way in which the form and questions are geared is that you answer yes and no. I don’t know what disease does recognise ‘yes’ and ‘no’, particularly chronic diseases. Life is not like that’

‘I want to go and give them a booklet about MS, they had no idea what it was’

‘[The assessor] was nice and understanding, however she just wanted to go through the set questions which were generic and did not cater individual illnesses’

For people with MS, the biggest change is the introduction of the 20 metre rule to decide who gets the most support with mobility. This has meant that people who are able to reliably walk even the smallest distance over 20 metre can no longer receive the highest rate. This has had the most significant impact on access to support for people with MS as shown by the concentration of people losing the highest rate of mobility: 59% of those ICM surveyed who had a decreased award had received less mobility support, compared to 31% who had a decrease in daily living. Looking at the rates of components specifically, by far and away the most common decrease was moving from higher to standard rate mobility, accounting for 47% of those who had lost support.

Decrease in rate of award for people with MS who were reassessed from DLA to PIP



The Government's own analysis supports the view that these reductions are because of the 20 metre rule. Within the Impact Assessment carried out when the criterion was introduced in 2013, the Government estimated that the change would mean over half a million (548,000) people in receipt of the higher rate of DLA mobility would see a reduction, while an additional 247,000 people receiving the standard rate of mobility would lose out completely.²⁴

The Government has consistently argued that the changes to disability benefits were intended to 'target support on those with the greatest need'²⁵. However, since the criteria were changed in 2011, no evidence has been presented by the Government to explain or justify the change or

how it targets support appropriately. No evidence has been produced to demonstrate a significant variance in the needs of those losing out from those maintaining support. Our research shows that far from correctly targeting support, many of those losing out indeed require the higher level of support to allow them to live independently. For example, many people with MS who need the support from the Motability scheme in order to maintain independence have been denied this, despite not being able to carry out daily activities without the vehicle.

Our survey also asked respondents to rate the impact of their MS on a number of activities including mobility. The average score amongst those who experienced a decrease in the mobility component was less than 1 point difference between those whose support had decreased and those who had stayed the same or increased (9.2 vs 8.3 out of 10). This also demonstrates clearly that a significant number of people who rate the impact of their MS on mobility 9 out of 10 have received a decrease. Indeed even among those who rate their mobility impact 10, 17% have received a decrease in their mobility component on reassessment from DLA.

Fluctuation not captured

Not only does the 20 metre rule use an arbitrary distance measure that seems unable to consistently or reliably indicate the greatest need – in too many cases it is also failing to consider and capture fluctuation and hidden symptoms, particularly pain and fatigue. Our survey reveals that the higher the level of fluctuation of MS symptoms, the more likely it is that the PIP award will decrease compared to the previous DLA award – 36% of people with MS who said their condition varies a lot saw a decrease in their mobility award, and 25% of people with MS who said their condition varies a little also saw a decrease in their mobility award. At the same time, 10% of those who said their condition does not vary at all also saw their mobility award decreased. For all these groups, only a small number of people saw an increase in their mobility award – 5%, 4% and 9% respectively.

The PIP assessment guide requires assessors to consider fluctuation of symptoms in relation to the descriptors they use during the assessment²⁶. Healthcare professionals carrying out the assessment should consider whether the ability of a claimant to carry out activities is impacted by their condition at least 50% of the days. However, since PIP was introduced, the Society has been highlighting repeated failure by assessors to consider fluctuation. In our MS Enough report in 2015, we asked survey respondents about their experience of the assessment – 26% of those who have had a face to face PIP assessment disagreed

that the assessor gave them the opportunity to explain the fluctuation in their MS symptoms and how this affects them differently from day to day or at different times of day²⁷. The continuing loss of award by people with MS with some or high levels of fluctuations points to a persisting problem – the PIP assessment is not able to fully capture fluctuation for claimants with MS.

‘PIP assessments do not take into account wide enough range and fluctuation of events. Too focussed on specific actions. Biased against unseen disabilities.’

‘I worry about the competence of the person doing the assessment, also their ability to appreciate living with MS and how it can affect you differently day to day depending on heat etc. And also the way doing everyday tasks can be very tiring. Also making assumption just because I look healthy’

Assessors must also take into account if a claimant can do an activity reliably. That means looking at whether the claimant can complete an activity safely, to an acceptable standard, repeatedly (as often as it is reasonably required) and in a reasonable time period. For example, preparing a meal without suffering burns or cuts (safely), without burning the food (to an acceptable standard), 3 times a day (as often as is reasonably required) and without taking hours to prepare each meal (reasonable time period). However, we also know that too often assessors do not apply the reliability criteria, and when it comes to the 20 metre rule – this criteria is more often than not assessed on watching the person with MS walk once from a car park to the assessment centre, without any consideration of the hidden symptoms this may be causing such as pain and fatigue, and whether the person can walk this distance again without having to rest, sometimes for prolonged periods.

Some of the healthcare professionals we spoke to said that the measure was leading to inappropriate outcomes because the distance was too short to assess reliable mobility with confidence.

‘...so I guess this comes under the point that this 20 metre measure doesn’t detect all the hidden symptoms or whether they can do that consistently and given symptoms like fatigue, I think that if I write a report and if I’ve got the evidence that they’ve got spasticity because I’ve assisted them or the physio has then I can talk about that, and I might talk about it from a functional perspective, so to get to work they can do this or they can’t do that. Whereas I would never mention directly if they can or can’t walk 20 metres consistently - what you can do today doesn’t mean you could do it yesterday or you can do it tomorrow. So that’s the problem with it, isn’t it? And so if they are only measuring it on a given time and place, most people will try their best on that day but what they don’t see is the next day they can’t get out of bed because they are so exhausted physically as a result’ – Occupational Therapist at the National School of Neurology at University College London Hospital

Current guidance allows for assessors to use informal observations as ‘part of a suite of evidence’²⁸ and does not explicitly need these judgements to be supported by other evidence. By using informal observations as evidence, assessors can ignore the reliability guidance entirely, ignoring the complexity of MS as a condition, its fluctuating nature, and the hidden symptoms that walking can induce.

‘You were observed to walk aided for 20 metre at a slow pace. That’s the key thing, that’s why I did not get it. I should have gone in a wheelchair and have someone tip me out like a wheelbarrow.’

‘As I have relapsing remitting MS it is difficult to say from one day to the other how the MS will affect me. I have pain and nerve difficulties in my feet and legs, but as this is not visible how can an assessor tell how I feel? Fatigue is also not a visible disability. I am concerned about the new mobility component,

as I can walk 20 metre with a stick but this doesn’t mean it is comfortable.’

Fluctuation and hidden symptoms, which should be considered by assessors, are too often ignored, or overlooked by using evidence from informal observations. This can result in incorrect decisions that are not based on the actual abilities of a person with MS, nor reflect the real level of need for support.

Aided versus unaided

Under DLA, decisions on award level were made according to how well, if at all, a claimant can perform an activity unaided – without the help of others or of devices such as walking frames. In contrast, under PIP if a person with MS can complete an activity with the use of an aid they are not considered to have a need for support. This is an important difference between the previous and current benefits, and may lead to many people losing the support they need. It is possible that due to this change in definition, a person with MS would have received the maximum level of support under DLA, only to see it completely slashed because they are able to walk a much longer distance with the use of an aid such as a Zimmer frame.

While clearly mobility aids help people with MS move around, we do not believe that they make the level of required support lower. Rather the opposite – the higher level of support is required in order to purchase and maintain mobility and daily living aids, and the need to use mobility aids also points to a higher level of expenses on mobility. For example, a person who can only walk with the use of a stick will probably need to spend more money on taxis than a person who can walk unaided, and could use public transport more easily.

The logic of denying support to people with MS who use aids and appliances to make their life easier is therefore flawed – yes, aids and appliances might bring a higher level of independence, but at the same time also point to a high level of restriction on mobility, which calls for a higher level of financial support.

Hilary, 64

Hilary lives in London. She was diagnosed in 2004 with relapsing remitting MS. Following diagnosis Hilary found it difficult to work, and eventually retired. Because of her MS, she has significant balance issues and has difficulty in getting around. Some of the medication she takes for a condition which is related to her MS makes her very tired, so going out needs to be planned in advance.

In the transition to PIP in 2017 Hilary lost the entire mobility component of PIP even though until then she received the higher rate of mobility support under DLA.

Treatments that have helped her with her mobility and balance such as Pilates have had to be cut because they are no longer affordable. Hilary lost her Motability car, and was told she will also lose her Blue Badge as she's no longer automatically eligible. Now she has her own car, Hilary rarely drives as her medication makes her tired which means she cannot drive for long periods of time. Keen to maintain her independence, Hilary socialises in central London often, but the reduction in PIP means that she is no longer getting support in paying the taxi fares.

'I have got the care component which I don't understand and I have no mobility which I also don't understand. I think the application is clearly biased to people have absolutely no mobility and in 100% care. So everything is on a scale, the way in which the form and questions are geared is that you answer yes and you answer no'

'The transition from DLA to PIP has now meant that I am £250 a month worse off. It is a huge impact in itself. As a consequence, my budgeting is now somewhat adrift. I have had to give up things that I would otherwise had done like Pilates. Really useful to me on the MS side, by increasing core strength and muscular strength to help with balance. To do Pilates in a mixed class and abilities is difficult as I tend to make mistakes and unable to overcome things I can't do, and I need more 1-1 support. Now 1-1 Pilates lessons probably £40 a week, can't do that now.'

'My friend moved 18 months ago and I have been unable to see her home and I feel really bad about that, but I am unable to get to her home unless I get a taxi, and I can't get a taxi to there and I can't justify taking a taxi there from here which would be quite a significant cost.'



The solution: Enough is enough – time for change

For five years, PIP has been failing people with MS. Despite the efforts of the MS Society and others to try and improve the system, people with progressive conditions like MS are continuing to lose support at an alarming scale.

The reduction in support due to the change from DLA to PIP has not been accompanied by evidence of a reduced level of need. Quite the opposite, even many people with progressive forms of MS, where need is most likely to increase, have seen reductions in the level of support they are getting, particularly for mobility.

Inappropriate criteria

The assessment criteria for PIP just don't work for people with MS. They cannot accurately assess the reality of living with a complex condition like MS that includes fluctuation and hidden symptoms.

For people with MS, the biggest change in PIP has been the introduction of the 20 metre rule. This measure of mobility means that people who are able to walk even the smallest distance over 20 metres can no longer get the highest level of financial support under PIP.

This even applies to people who received this level of support for many years under the predecessor benefit DLA. However, the Government has never been able to produce any evidence that people who can walk over 20 metres have lower levels of need for mobility support.

This inappropriate criteria, which is often assessed by watching a PIP claimant walking from a car park to the assessment centre, has resulted in significant losses of support for people with MS, which often means the loss of the lifeline to the outside – the Motability vehicle.

The assessment process

Since PIP has been introduced we have continually been hearing from people with MS who tell us that the assessment process fails to capture the reality of living with MS.

Most people with MS go through a face-to-face assessment, but assessors too often have little knowledge of MS, and ask generic questions that cannot capture hidden symptoms such as pain and fatigue.

While some incremental changes have been made to the assessment process since PIP has been introduced, and a number of reviews of PIP have taken place, our research shows that people with MS are still telling us of the same problems we have described in our 2015 MS: Enough report.

The impact

The inappropriate criteria and the flawed assessment process result too often in a reduction in support for those who need it most.

Even people who received an increase in support have reported that the whole process has negatively affected their emotional and physical wellbeing, their financial security and their overall day-to-day life.

Mobility is also significantly impacted, especially by people who receive a reduction in support. In particular, the loss of the highest rate of support means the loss of a Motability car or scooter. Looking after children, working, and going to hospital appointment can all become difficult without this type of mobility support for people with severely impaired mobility.

This report also reveals the staggering effect on services. The extra expenditure for the NHS and the level of support sought from charitable organisations such as the MS Society suggest a transfer of costs from one governmental department to another, as well as to the third sector.

Senseless change

All this suggests that the change in criteria under PIP does not make sense for people with MS, and rather than allowing people with MS to be independent, it is taking it away from them.

The healthcare professionals who took part in our research agreed that the assessment process and the 20 metre rule do not work for people with MS, who live with a degenerative neurological condition, and are unlikely to have seen their situation get better since they were on DLA. The Government says they want to target support through PIP at those who need it the most, but instead support is being taken away from people who healthcare professionals know still need the highest level of support.

We don't know how much the changes to PIP cost to other services overall, but our evidence from this research suggests that the NHS and other services are absorbing large costs brought on by the change to PIP. When scaling to other conditions those figures are likely to increase much more and makes the change all the more senseless.

What can be done

To ensure that PIP properly supports people with MS, a number of changes to the process and criteria are necessary.

The assessment itself requires change, so that it can effectively capture the reality of living with MS. A more open discussion, rather than rigid questioning, is a good start. Taking into account medical evidence from healthcare professionals and listening to friends and family tell how people are affected by their MS is also essential to getting a real understanding of how the condition affects the ability of people to do daily tasks and to move around.

Assessors with knowledge of MS will also help in delivering assessments that accurately assess fluctuation, and hidden symptoms. The assessment of these, as well as reliability must be written into each criteria to ensure this is done at every assessment.

Scrap the 20 metre rule

The biggest change for people with MS is the 20 metre rule. In order for PIP to deliver the right level of support for people with MS, the Government must scrap the 20 metre rule.

The Government must carry out a review with disabled people, charities and healthcare professionals to design an agreed appropriate alternative to the measure. We do not suggest here what this measure could be, but we believe that while this review is ongoing, the Government should reinstate the 50 metre threshold as under DLA.

Enough is enough – PIP must change. People with MS deserve to receive adequate support that allows them to live an independent life as much as their non-disabled peers do. PIP must change to reflect the realities of living with MS. It must change so that people with MS can continue to be able to manage their condition as best they can, and receive the medical care they need. PIP must change to ensure that the families and friends of people with MS are not negatively impacted by the financial insecurity of their loved ones.

Enough is enough – we call on the Government to listen to people with MS and to change PIP so that those with need always receive the right level of support.

Enough is enough – scrap the 20 metre rule.



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To find out more about our MS: Enough campaign to make welfare make sense, visit mssociety.org.uk/msevenough



We're the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

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