

The background features a large, abstract geometric shape in the center, resembling a stylized arrow or a speech bubble, filled with a gradient of orange and yellow colors. This shape is surrounded by thin, dark orange lines that form a network of interconnected paths, creating a sense of movement and connectivity. The overall design is clean and modern, with a focus on geometric forms and a warm color palette.

**Improving MS treatment,  
care and support: a  
manifesto**

November 2019

Let's stop MS together

## Improving MS treatment, care and support: a manifesto

More than 100,000 people live with multiple sclerosis (MS) in the UK. MS can be relentless, painful and exhausting. It's a condition which damages nerves in your body, making it harder to do everyday things like walk, talk, eat and think. Symptoms can fluctuate, making life unpredictable. They can include loss of balance, stiffness, spasms, speech problems, fatigue, pain, bladder and bowel, and vision problems.

Living with MS is also expensive. It costs, on average, an extra £200 a week to live with a neurological condition like MS. MS affects three times as many women than men, and typically starts affecting people at pivotal times in their professional and personal lives. Some people with MS will need social care and welfare support to continue to live well independently.

Treatments for MS have revolutionised what it is like to live with the condition today. However, many still face barriers accessing effective treatments. And for too many people with MS there are no disease modifying treatment (DMTs) available.

We are the largest UK charitable funder of MS research, and hope the UK Government will do their part to accelerate progress in this field too. We are currently fundraising for our most ambitious research programme yet. When we meet our target, our new trials platform will test repurposed medicines in thousands of people living with progressive MS who currently have no effective treatment to slow or stop disease progression.

We estimate the UK Government spends over £1bn on various forms of support for people living with MS. Yet many people with MS don't get the support they need from the NHS, social care or disability benefits.

There are clear opportunities to improve treatment, care and support for people with MS. And to look at government spending to make sure it goes as far as it can to help people keep their independence.

## Our priorities for the next UK government

We work closely with our MS community to understand current gaps in treatment, care and support, and some of the burning issues that need acting on. We're calling on political parties to listen to them and adopt key recommendations to improve Personal Independence Payments (PIP), our social care system and access to cannabis-based medicines.

## Key principle #1 - Improving UK research infrastructure

It is our number one goal to ensure people with MS have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability.

Our adaptive clinical trials platform, supported by world-leading experts in MS, is the first of its kind in neurology and will allow us to test many potential treatments simultaneously to slow (and ultimately stop) the progression of MS.

Adaptive clinical trials allow researchers and clinicians to test multiple drugs simultaneously and have the potential to find life-changing treatments for conditions like MS significantly faster.

**The UK government must invest in UK research infrastructure and life sciences to remain at the forefront of innovation and a global leader in science. This will include matching any research and development spending lost through leaving the European Union.**

## 1. Make PIP make sense

Personal Independence Payment (PIP) is a disability benefit that is supposed to help people manage extra costs associated with disability. But all too often it fails people with MS.

People with MS frequently report their assessor did not understand their MS. Strict assessment criteria, like the PIP 20 metre rule, mean people are denied vital support. Our research found the rule is predicted to save the UK Government £26.9m over the next year as a result of cutting PIP support from people with MS. However, we predict this will be outweighed by £30.2m in just some of the knock-on costs to UK Government in this same period.

**The UK government must scrap the PIP 20 metre rule and review the entire PIP assessment process to make sure it makes sense for people with conditions like MS.**

PIP is one in a series of benefits being devolved to the Scottish Government between now and 2024. Whilst that process is ongoing the UK government should look to adopt the improvements in application and assessment proposed by the Scottish Government and seek wider improvements such as better assessor expertise

## 2. Create a social care system that works for everyone

One in three people with MS struggle without the support they need to do the basics like getting washed, dressed and eating. This prevents them – and their family members and friends providing unpaid care – from living dignified, independent lives.<sup>1</sup> This is not fair and it is unsustainable. Social care funding in the UK has not kept pace with increasing demand and we now face a huge shortfall, with too many people with MS shut out of the system.

**The government must ensure care and support is sustainably funded across the UK and commit to reducing unmet need. That includes bringing forward a plan to create a sustainable system in England, in which care is free at the point of need and fully funded through taxation, with the costs spread fairly across the population. This would mean more people are able to access quality care when they need it and ensure cost is not a barrier to anyone getting the support they need.**

## 3. Ensure people with MS have access to the cannabis-based medicines that can help them manage their condition

Despite the change in the law in 2018, access to cannabis-based medicines remains extremely limited. Sativex is a licensed cannabis-based drug for MS related muscle spasms, but is not routinely available on the NHS across the whole of the UK. This means many people with MS struggle to afford a private prescription.

People with MS report frustration and disappointment in being denied a treatment that could help them manage symptoms. People are being driven to break the law to source illegal forms of cannabis, which is unregulated and dangerous. Smoking street cannabis with tobacco can speed up the progress of someone's MS. It shouldn't be illegal to get the relief you need. This is an intolerable situation that must change.

**We need a cross-government plan on cannabis-based medicinal products to encourage more research and educate health professionals, so people with MS can access these treatments to manage pain and spasticity.**

## Key principle #2– a NHS and care workforce

To make sure people with MS get the right treatment and care, we need a NHS that can support the needs of people living with MS today and into the future. We need the next government to invest in our NHS and the health professionals that support us. Current workforce pressures are a serious cause for concern.

There are not enough neurologists and specialist nurses in the UK. There are 6 times as many neurologists per patient in Europe than there are in the UK, and too many specialist nurses have unrealistic caseloads<sup>1</sup>. We need long-term investment in the training and numbers of neurologists and specialist nurses to make sure everyone with MS can access the clinical care they need when they need it.

But we can also invest in more administrative and support staff, and the upskilling of existing staff, now to enable specialists to spend more time with patients than paperwork. Investing in the tools, technology and IT infrastructure surrounding specialists will also help to free up their time and improve care for people with MS, from self-management tools and virtual clinics to better sharing of data.

**We need a NHS health and social care workforce plan for the UK that prioritises neurology, commits to action to address the serious shortage of specialists and make the most efficient, effective use of the existing specialist workforce.**

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<sup>1</sup> Ref: Morrish PK, Inadequate neurology services undermine patient care in the UK, BMJ 2015;350:h3284 doi: 10.1136/bmj.h3284



## 1. Make PIP make sense

“When I think about the decrease [in my PIP support] I feel 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 am trying 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.”

Salah, 41 (diagnosed with MS in 2002)

### What we need to see from the UK government:

- **Scrap the PIP 20 metre rule**
- **Review and improve PIP to recognise the complex nature of conditions like MS**



### Background

Since 2013, PIP has started to replace the Disability Living Allowance (DLA). PIP is a disability benefit designed to help people living with a condition like manage the extra costs associated with their condition. It is meant to provide people with MS with vital

support to live full and independent lives - *to live rather than exist*. But, too often the PIP process fails people with MS.

The complex nature of MS makes PIP difficult to assess, particularly when the claim process is designed in a way that doesn't allow people with MS to fully explain how the condition impacts their lives on a daily basis. Our research shows more than half of people with MS surveyed didn't feel their assessor understood their MS<sup>2</sup>.

Too often, assessors make inaccurate decisions based on 'informal observations' - the way people look or act during their assessment. Our surveys show 67%<sup>3</sup> of people with MS whose assessment included an informal observation said it didn't reflect how MS affects them. Assessments should be carried out by people with good knowledge of a person's condition.

As a result of failures in the PIP process, people with MS are going through exhausting, demoralising and unnecessary appeals. 83%<sup>4</sup> of people who move from DLA to PIP and challenge their decision win their appeal.

### PIP 20 metre rule – a step too far

One of the biggest changes since PIP was introduced has been the introduction of the PIP 20 metre rule. This means that people who can walk one step over 20 metres are not entitled to qualify for the higher level of mobility support. Under the DLA, the measure was 50 metres.

However, our research reveals that losing out on PIP has very serious implications for people with MS in terms of their health and employment, and it doesn't save the government the money it had intended. At the time the PIP 20 metre rule was introduced, the Department for Work and Pensions (DWP) said it had consulted with other government departments and that there would not be 'any significant additional cost implications in their areas' (including the Exchequer, and to the DWP itself).

Our research has shown that the UK Government are expected to save £26.9m over the next year as a result of cutting PIP support from people with MS. However, we predict this will be outweighed by £30.2m in just some of the knock-on costs to the UK Government in this same period.<sup>5</sup>

The 20 metre rule means that people with MS have been losing out on vital support. Support cuts that our research has shown does not cut the cost to the taxpayer.

**We need a PIP process we can trust. Decisions need to be backed up by evidence not assumptions. Assessments need to be carried out by professionals with good knowledge of MS. And assessment criteria should truly reflect the realities of living with MS.**

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<sup>2</sup> MS Society, *The Cost of PIP*, 2019

<sup>3</sup> MS Society, *Survey of people with MS*, 2019

<sup>4</sup>Hansard, Stephen Timms PQ, 16 October 2018, available online via: <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2018-10-16/180082/>

<sup>5</sup> MS Society, *The Cost of PIP*, 2019

## 2. Create a social care system that works for everyone

“My MS started worsening about five years ago. I can’t get out of bed myself, overnight my legs really stiffen up and I can’t move them at all in the morning. It took nearly a year from the point of approaching social services to my care being in place. I was told no care agencies had availability. I was phoning social services every few days asking ‘what am I meant to do?’ I work part-time as an accountant, so I need a carer at 7am every morning to help me shower. They said they’d tried everything and couldn’t do anything more. I felt completely lost.”

Edith, 30, living with MS

What we need to see from the UK government:

- **A fair and effective care system that works for everyone, no matter how old they are**
- **A social care system that is free at the point of need and funded through our taxes**
- **A consistent assessment process so access is fair no matter where you live**
- **A ‘moderate’ eligibility criteria, so people do not have to wait to get worse before they get help**
- **More support for unpaid carers, including increased funding for breaks, Carer’s Allowance and other carers’ benefits**





## Better care for people with MS

One in three people in England with MS struggle without the support they need to carry out essential activities<sup>6</sup>. This prevents them – and their unpaid carers – from living independent, dignified lives, and accessing volunteering or paid work (for those who can). They face multiple challenges accessing quality care, because their needs are not deemed ‘bad’ enough to qualify for support, they cannot afford care or local provision doesn’t meet their complex and often fluctuating needs.

Too many people with MS are ‘shut out’ of the system, because their needs are not high enough to be eligible. It does not make sense to wait until a person’s health or wellbeing has deteriorated before providing support. Lowering eligibility for care to enable more people to access it would cost upwards of £8bn in 2023/24.<sup>7</sup>

Currently, no one can protect themselves from unpredictable, potentially huge care costs. By sharing the costs of care across society we can all be protected from this risk. Making care free at the point of need would prevent cost being a barrier to people getting essential support and would cost upwards of £7bn in 2020/21.<sup>8</sup>

Finally, any long-term plan to put social care on a sustainable footing cannot afford to neglect the combined millions of working-age adults and carers who need support. Local authorities spend almost the same amount supporting working-age adults living with disability as they do supporting older people, but many working-age adults with MS face particular challenges finding age-appropriate care.

## Better support for unpaid carers

According to our ‘My MS My Needs’ 2016 survey of 11,000 people with MS in the UK, 85% of people with MS who have care and support needs, receive support from a family member or friend, unpaid. Overall, family and friends providing unpaid care save the State at least £49bn a year across the UK.<sup>9</sup>

However, families are under increasing and unsustainable strain. As social care has become harder to access, more have had to step in to fill the gaps often at the expense of their own wellbeing. A survey of family and friends of people with MS in 2019 found 48% of respondents felt they did not get any or all of support they needed, while 19% said an existing health condition had got worse in the past 12<sup>10</sup> months as a result of providing support.

People are often diagnosed with MS during the prime of their working lives, when they may be raising a young family too. That impacts on partners who may themselves be working, as well as young children who could find themselves taking on inappropriate caring responsibilities. For people with fluctuating forms of the condition, this provides distinct challenges, as family carers may not know what support they will need from one day to the next.

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<sup>6</sup> MS Society, Social care and the MS community in England, March 2017

<sup>7</sup> House of Lords Economic Affairs Committee, Social care funding: time to end a national scandal, 4 July 2019

<sup>8</sup> The King’s Fund, A fork in the road: Next steps for social care funding reform, May 2018

<sup>9</sup> New Economics Foundation, Socioeconomic Costs and Benefits of Unpaid Carers, 2019

<sup>10</sup> MS Society, Family and friends survey, 2019

**We need a fair and sustainable care system that works for everyone no matter their age, in which care is free at the point of need and fully funded through taxation, and access is expanded. We also need increased practical and financial support for unpaid carers of people with MS, who cannot be expected to do more than they already are. This would mean more people with MS are able to access quality care when they need it and relieve unsustainable pressures on family and friends**

### 3. Make sure people with MS have access to cannabis-based medicines that can help them manage their condition

“Sativex is the only thing that’s given me pure relief from the pain and muscle spasms. I’ve spent nearly £12,000 on this over two years. I’ve had to ask my family to help pay for it and it’s been worth every penny. It’s not only given me my body back, it’s given me my life back. I stopped taking Sativex around four years ago because of the cost. I’m on benefits and was using DLA to pay for it. My mum, dad and grandma were helping too... This was just too much and I couldn’t keep putting it on my family. I’ve really struggled since coming off it...”

Donna, 41, diagnosed with MS in 2013

What we need to see from the UK government:

- **To publish a clear cross-government plan on cannabis-based medicines that sets out how government intends to encourage innovative research, educate health professionals, and give people with MS access to these treatments.**
- **Speed up research into cannabis-based medicines in the UK. Alongside new trials, a new government should establish a managed access scheme on the NHS, which gives timely access to products that could help the 10,000 people with MS who could benefit.**
- **Start discussions immediately with the companies responsible for Sativex to make it available on the NHS, across the UK, as soon as possible.**



## Background

In November 2018, the UK Government made it legal for specialist doctors to prescribe cannabis-based medicinal products in the UK for people with MS. However, in reality, nothing has changed. To our knowledge, nobody with MS has benefitted from the change in the law, and access to cannabis-based medicinal products remains very limited.

Dealing with pain and muscle spasms when you have MS can be relentless and exhausting. Evidence shows that cannabis for medicinal use could help people with MS manage pain and muscle spasms (spasticity) when other treatments haven't worked for them. One in five people with MS we surveyed have tried cannabis for medicinal purposes. Our medical advisors estimate 10,000 people in the UK could benefit from cannabis-based medicinal products.<sup>11</sup>

Sativex is a cannabis-based medicine used to treat the common MS symptom of muscle stiffness and spasms (known as 'spasticity'). Around half of the people in one study found it reduced their symptoms by 20% within four weeks.

However, Sativex is not currently available on the NHS across all four nations of the UK, meaning some people with MS struggle to afford a private prescription costing hundreds of pounds a month. It isn't right that access to this treatment can depend on where you live in the UK.

The new UK government – along with governments in devolved nations - should get around the table with Bayer (the company responsible for Sativex) to make it available on the NHS across the UK.

**It shouldn't be illegal to get the symptom relief you need. We need UK Government to step up and address access to medicinal cannabis now, and support research so people with MS are able to get the treatments they need in future.**

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<sup>11</sup> MS Society, [Cannabis and MS](#), July 2017

**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.

[mssociety.org.uk](http://mssociety.org.uk)



**Disclaimer: in line with the Transparency of Lobbying, Non-party Campaigning and Trade Union Administration Act 2014, we will be issuing this manifesto to all main UK political parties**

**Contact us**

If you have any questions or would like to arrange a meeting to discuss the contents of this Manifesto, please contact Joe Brunwin (External Relations Officer) on [joseph.brunwin@mssociety.org.uk](mailto:joseph.brunwin@mssociety.org.uk) or 020 8438 0866

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