A lottery of treatment and care – MS services across the UK
We’d like to show our appreciation to those without whom we could not have completed this report – a thank you 10,530 times over (pg. 6) to the people with MS who took the time to respond to our research.

Inside this report, you’ll find a word from our Acting Chief Executive (pg. 5) followed by the executive summary (pg. 8).

The remainder of the report will look into the issues we face across the whole of the UK and look at how the four nations of England, Wales, Northern Ireland and Scotland compare. We focus on: Access to medicines (pg. 10); care and support (pg. 14); financial security (pg. 18); and physical and mental wellbeing (pg. 22).

Finally, we look at next steps (pg. 28), taking a look at the questions raised by our research and what must be done (pg. 30) to address them and who we must bring along with us to beat MS.

And, as you’d probably expect, at the very end you’ll find our references (pg. 32).

If you only have time to take a quick look at this report, skip straight to the executive summary (pg. 8) and then look at what must be done (pg. 30).

Please note that although we use the abbreviation “NHS” throughout the document, we do of course generally include HSC of Northern Ireland within that shorthand.
WHAT IS MULTIPLE SCLEROSIS (MS)?

Approximately 100,000 people in the UK have multiple sclerosis. Every one of them shares the uncertainty of life with MS. MS attacks at random and many of the symptoms are invisible to others. It affects almost three times as many women as men, and you’re usually diagnosed in your 20s or 30s; news that can be scary and heartbreaking.

People with MS live with great uncertainty, not knowing from one day to the next whether they will be able to move, to see or to live even a remotely normal life. There are several forms of MS and it is different for everyone – symptoms might include fatigue, vision problems, difficulties walking or speaking, tremors, dizziness, memory problems and depression. It can lead to severe and permanent disability. The most common form is relapsing remitting MS (RRMS), which affects around 85 per cent of those diagnosed. Symptoms appear – a relapse – and then fade away, either partially or completely. A relapse may last for a few hours, or many months. It might be relatively mild or require treatment in hospital. Many people make a good recovery, but around half experience lingering problems. Most go on to develop ‘secondary progressive MS’ – a sustained build up of disability over time, independent of any relapses.

Around 10-15 per cent of people are diagnosed with ‘primary progressive MS’ – in which the condition gradually worsens from the point of diagnosis, rather than appearing as sudden attacks that come and go.

The causes of MS are unknown and there is currently no cure. Although biomedical research is paving the way towards potential new treatments in the future, the treatments available today don’t work for everyone and don’t work all the time.

BACKGROUND ON THE MS SOCIETY

The MS Society is the UK’s leading MS charity, with around 38,000 members and 300 branches across the country. We’re working to improve treatment and care to help people with MS take control of their lives.

We’re working with partners around the world to fund research that we believe will beat MS for good. We’ve already made important breakthroughs, and we’re now at the start of a generation of MS research that holds incredible promise.

While we work towards a cure, we’ll continue to fight the corner for people affected by MS – demanding the highest quality care and support, wherever they live.

With your support, we will beat MS.

A WORD FROM OUR ACTING CHIEF EXECUTIVE

This report should be a sobering wake-up call for all of us working to improve the lives of people with MS in the UK.

When we began this unprecedented research project late last year – gathering evidence about access to health, social care, employment and welfare services from more people with MS than ever before – we anticipated we would uncover shortcomings and disparities in the services offered from one part of the country to another.

We could not, however, have anticipated the scale of some of those shortcomings or the degree to which access to services would vary.

Some of the statistics in this report are nothing short of shameful. Perhaps most concerning is that as many as six out of 10 people with relapsing forms of MS are currently going without any form of disease modifying treatment. Across Europe, only Poland and Romania fare worse.

Worryingly, our report consistently shows that the more financially worse off people with MS are, the less likely they are to get access to services they need – whether that is social care, physiotherapy, mood and emotional support, or aids and adaptations, such as wheelchairs.

There are areas where there is better news, and some beacons of hope that we could highlight and celebrate. It’s reassuring, for example, that on the whole, people with MS appear to have access to a broad range of MS specialists – although one in five rarely or never find it easy to see a specialist when they need to.

Northern Ireland is leading the way in this area – it’s the only place in the UK where most people with MS see a neurologist or MS nurse for a routine review every six months. This should be replicated across the UK so that people have regular and timely access to a range of MS specialists throughout their lives, providing specialist input, information and referral to relevant services when they’re needed most.

As the MS Society marks its 60th anniversary in 2013, we can’t help but reflect on the undeniable improvements we’ve witnessed in the way MS is diagnosed and treated over the last 10 – 20 years. But the pace of improvement is far too slow. More needs to be done to ensure services are more responsive, timely and better meet the needs of people with MS.

If we want the UK to be a place where people with MS can be supported to take back control and live the full, independent lives to which they are entitled, we urge decision makers at a local and national level to take heed of this report and act on its recommendations.

Patricia Gordon
Acting Chief Executive
THANK YOU, 10,530 TIMES OVER

This report would not have been possible without the 10,530 people who gave their time to complete and return our survey.

We would also like to thank our members who have shared their stories and helped us show how the statistics reflect real life. Our research exposes the current lottery of treatment and care, but their contributions articulate its everyday impact more eloquently than data could ever do.

The views of our members are the backbone of this report, which illustrates their needs and highlights the areas where health and social care services are falling short.

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EXECUTIVE SUMMARY

ACCESS TO MS MEDICINES

- Six out of 10 eligible people do not take disease modifying treatments (DMTs).
- Two symptom management treatments had been recently licensed for MS at the time of our research – but only one in 50 people with MS takes these.
- If you have MS and live in Northern Ireland you are more than twice as likely to be taking a DMT than if you live in Wales.
- Across Europe, only Poland and Romania have a smaller proportion of people with MS taking DMTs.
- Those who feel they have enough information about medicines are 32 per cent more likely to be taking a DMT. (59 per cent compared to 27 per cent).
- Access to specialists also plays a key role – those with access to an MS nurse or neurologist are more than twice as likely to be taking a DMT.

We want people with MS in the UK to have access to medicines that are among the best in Europe, not the worst, and to see an end to the current postcode – and passport – lottery of access.

To do this we are calling on governments across the UK to ensure every person with MS has a personalised treatment, care and support plan, with two comprehensive reviews each year.

CARE AND SUPPORT

- Only half of people with MS (53 per cent) who are really struggling financially have their need for social care met, compared to nine out of 10 (86 per cent) who are financially really comfortable.
- Half of those who pay for all their social care faced increasing costs over the past year.
- 71 per cent of people with MS get unpaid care, support or assistance from a friend or family member and nine out of 10 need assistance from others.
- Those with a carer are 11 per cent more likely to need additional social care but are four per cent less likely to receive it.
- 45 per cent of people with MS who feel their carer needs a carers’ assessment were offered one; and for those who are really struggling financially this falls to just 37 per cent.

We are calling for personal and social care needs to be met through the same entitlement to free services as applies to healthcare, irrespective of age.

All four governments must provide adequate funding for social care authorities so people with MS can access the services they need and retain their financial security. The current income-based variations in access to social care are not acceptable.

For governments to establish quality standards for social care similar to those used to drive up standards for healthcare. A key aspect of quality must be genuine shared decision making in care planning.

Preventative support for those with lower level needs should be an entitlement, not a luxury.
We also call for proper recognition of, and support for, informal, unpaid carers, who provide vital support for people with MS, yet are taken for granted by too many care providers and by government. Carers’ assessments must be routinely and consistently provided and supported by timely and responsive services.

FINANCIAL SECURITY

Employment:
- A quarter of people with MS who are of working age are employed, compared to three quarters of the wider UK population.
- Only 25 per cent of unemployed people with MS who want support to find paid employment are able to get it.
- Access to support to find, and hold on to, paid employment varies considerably across the UK. People in Scotland and Wales, who feel they need it, receive notably less support.

Benefits:
- Eight out of 10 (82 per cent) of those who took part in our research receive Disability Living Allowance (DLA).
- 78 per cent of people getting DLA have a friend or family member who provides unpaid care, support or assistance.
- Of those who receive DLA, 66 per cent need frequent or constant assistance compared to just 10 per cent of those not receiving DLA.
- Of people on DLA, 18 per cent are struggling financially. This is twice the number (nine per cent) of those who don’t get DLA.

We expect 46,000 people with MS who are of working age to be reassessed for the Personal Independence Payment (PIP).

Many people with MS can – and want – to work, but we need to do much more to help people to stay in employment, with occupational therapists crucial to unlocking much of what can be done.

For those who are unable to work, or need extra support to stay in work, financial security is dependant on the ability to access appropriate benefits. Benefits are also vital for covering the additional costs of being disabled, which in turn help people to remain independent.

We therefore insist that assessments for benefits such as ESA and PIP recognise the needs of people with fluctuating conditions such as MS.

PHYSICAL AND MENTAL WELLBEING

- There is a worrying inequality in access to emotional support, physiotherapists and continence advisors that corresponds directly to income. For example, only 33 per cent of those who are really struggling financially get sufficient emotional support, compared to 72 per cent of those who are really comfortable.
- 78 per cent of those who are usually or always asked what is important to them by professionals who help manage their MS had their need for emotional support met. In contrast only 30 per cent of those never asked had this need met.
- Physiotherapists are essential for facilitating support to remain physically active. Those with a physiotherapist are nearly twice as likely to have their need to access support to remain physically active met.
- People who are able to see a specialist, particularly those who find it easy, feel better informed about their MS.

Being empowered, involved in your care and well informed is key to physical and mental wellbeing. Our research reveals a postcode lottery of access to specialists and a worrying inequality of access linked to income; which is why we are calling for regular and timely access to all specialists.
Six out of 10 eligible people with MS are not taking medicines which can alter the course of the condition. There is also considerable variation in access to treatments between the four nations.

Disease modifying treatments (DMTs) were first licensed in the UK in 1995, but not made available on the NHS until 2002. So, until 2002, people diagnosed were generally told they had MS and to go away and learn to live with it. They were typically just given painkillers and relapses were treated with steroids (which had severe side effects). 

In 2002, following doubts about the cost effectiveness of the new treatments, the National Institute for Health and Clinical Excellence (NICE) asked the drug manufacturers and the Department of Health to find a way to enable access to the treatments across the UK. The landmark MS Risk Sharing Scheme was the result, making a group of four treatments available on the NHS, throughout the UK.

In 2007 and 2012 respectively, Tysabri and Gilenya were approved for use on the NHS across the UK. Tysabri, a monthly infusion administered by a healthcare professional, reduces the number of relapses by an estimated 67 per cent and slows disability. Gilenya, the first pill for MS, reduces relapse rates by 54 to 60 per cent and slows disability\(^2\) progression by around 30 per cent.\(^3\)

Treatment options were further expanded with the licensing of three important symptom management treatments (SMTs); Sativex in June 2010 and Fampyra and Botox in 2012.

But shockingly, despite clinical trials consistently showing these treatments reduce relapses (to varying degrees), slow progression of the disease and help people with MS cope with symptoms, our research shows only 40 per cent of eligible people with MS take one of the seven DMTs currently licensed and approved for use in MS.

Based on NICE estimates around 510 people with relapsing remitting MS who took part in our research could benefit from Gilenya, but only 25 people – five per cent of those eligible for the treatment – are actually taking it.

Although it was approved for use on the NHS six years ago, there is a similar gap between eligibility and access to Tysabri. We estimate that around 689 people who took part in our research should be on this treatment, but only 203 people – 29 per cent of those who are eligible – are taking it.

Access is a postcode lottery. The reality is that if you have MS and live in Northern Ireland, you are twice as likely to be taking a DMT than if you live in Wales. Access to treatment in Scotland and England was almost as bad as Wales.

Proportion of those eligible taking DMTs

68% in Wales

40% in Scotland

30% in England

40% in Northern Ireland

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40% in Scotland

30% in England

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Access to the right treatment at the right time is a fundamental right. The MS Society believes that every person with MS must have equal access to treatment, and we have fought hard to present a robust case for these medicines to be made universally available on the NHS.
There is no doubt that symptom management treatments (SMTs) can make a huge difference to people's everyday lives, by helping control problems such as spasticity and walking, which can seriously impact quality of life. But access to Sativex – the UK's first cannabis-based licensed medicine – and Fampyra – which can improve walking speed by 25 per cent – is abysmally low. Only two per cent of people with MS have access to these life-changing treatments.

Since our research, Botox has been licensed to treat MS, and Fampyra, a licensed medicine – and Fampyra – has been licensed to treat overactive bladder, adding another choice for people with MS. Inconsistency in decision-making at a local health authority level also impacts upon access. For example, in February 2011, the Midlands Therapeutic Review and Advisory Committee (MTRAC) – an independent advisory group that provides guidance on pharmaceutical treatments to PCTs in the West Midlands – recommended against prescribing Sativex. It claimed Sativex “cannot be recommended for prescribing because of inadequate evidence for efficacy and/or safety”.

This decision is based on an inaccurate analysis of the data, and on the cost impact of the treatment rather than cost effectiveness. But despite writing to them to point this out, and the fact that the decision contradicts the extensive appraisal carried out by the Medicines and Healthcare Products Regulatory Agency (MHRA), the national regulatory body, the Committee has not reviewed its policy.

The shockwaves of this decision have spread way beyond the Midlands, and have triggered a proliferation of similar decisions from other regional bodies. As a result, people with MS are being denied treatment or struggling to access a treatment that has the potential to significantly improve their quality of life.

Accessing SMTs, which can make the difference between working or relying on welfare, is often a battle. People living with MS face a continual struggle against the condition; they should not have to struggle against the health system, too.

**OUR CALL**

- Ensure every person with MS has a personalised treatment, care and support plan, with two comprehensive reviews each year. These reviews should be led by an MS specialist who can ensure that treatment options are reviewed on an ongoing basis; that individuals have access to information to help them make informed choices; and so they can be referred to the health and social care services required to meet their needs. These reviews should occur regardless of whether a person is on treatment and should be in addition to other appointments made at the point of need, for example, experience of a relapse or a significant change in symptoms.
- The reviews need the backing of systematic, integrated commissioning, so coordinated, multi-disciplinary care becomes a reality.
- The Association of British Neurologists (ABN) should build on their established professional leadership and update the 2009 prescribing guidelines for MS. These prescribing guidelines should be updated after the publication of any further guidance (by statutory regulators) on new treatments.
- Local health authorities must avoid blanket bans on approved medicines and make recommendations on a case-by-case basis according to individual needs and circumstances. In doing so they should respect the decisions made by the (MHRA) and European Medicines Agency (EMA) on the safety and efficacy of treatments.

**FIGHTING FOR NEW TREATMENTS**

Chris Ray, 53, lives in Bromsgrove and was diagnosed with Primary Progressive MS three years ago. In December 2012 she was prescribed Fampyra, a licensed treatment which improves walking ability and speed in people with MS, but has to pay £230 a month to get it.

She says: “This treatment has given me my life back – it has made a huge difference to my walking, I’m much quicker and more efficient now, which means I’m not as fatigued. Before taking the treatment I was on the verge of depression and was thinking about giving up work: I just didn’t have the energy – but that’s all changed. I work 16 hours a week and can’t afford the treatment on my own so I’m fundraising to help pay for it; it’s unfair.”

Grace Rodgers, 52, from Belfast, was diagnosed with relapsing remitting MS in 2007. Three years ago her neurologist applied for her to receive Sativex on the NHS, but her request was refused. She submitted more evidence, but again her local Health Trust declined to fund the treatment.

She said: “I have spasms and pain because of my MS. I just want the chance to try Sativex, but I’ve all but given up on getting it now. It’s not fair that some people get access to MS treatments and others don’t. It makes me so angry. I feel like giving up because the end result is always the same, a postcode lottery that I never win.”

**OUR PLEDGE**

We will:

- Work with a number of partner organisations to better define the pathway of treatment, care and support that every person with MS should expect to benefit from.
- Empower people with MS to make informed choices on their treatment by continuing to provide up-to-date information and decision-making tools.
- Monitor prescribing rates for any evidence of variation in access and challenge treatment policies where concerns are identified.
- Speak directly to decision makers across the four nations, with a strong, clear voice, to improve access to effective MS treatments.

**SYMPTOM MANAGEMENT**

**MILESTONES**

Before 2002, steroids were the only treatment option through the NHS, though from 1995, when interferon beta-1a was licenced, some people bought treatment privately.

2002 – Launch of the MS Risk Sharing Scheme. Four DMTs – Avonex, Betaseron, Rebif and Copaxone – were provided on the NHS across the UK, according to the ABN prescribing guidelines.

2007 – Tysabri approved by NICE for the treatment of rapidly evolving severe relapsing remitting MS.

2008 – NICE guideline for Tysabri endorsed in Northern Ireland by the Department of Health, Social Services and Public Safety (DHSSPSNI).

2009 – another DMT, Extavia, licensed for MS.

2012 – Gilenya, the first pill for highly active relapsing remitting MS, approved by NICE, recommended in Scotland by the Scottish Medicines Consortium, and funded in Northern Ireland by the Department of Health, Social Services and Public Safety (DHSSPSNI).

2013 – NICE announced they will appraise four new treatments, three of which are pills, assuming they are granted licences.

**OUR HOPE**

With four new MS medicines on the horizon, it is more important than ever that every person in the UK who has MS is able to access the right medicines at the right time.

We believe people with MS in the UK should be among those having the best access to medicines in Europe, not be counted among those with the worst. And if these new treatments are approved, access must be based on need, not a person’s address.
CARE AND SUPPORT

The dividing line between healthcare and personal or social care has always been rather arbitrary and has changed over time, particularly with a long-term effort to care for people outside the hospital setting.

There is, therefore, no straightforward and consistent way to define a person as needing nursing care or personal care or other support. In practice, people are defined subjectively and often according to organisational pressures. The interests of the person being cared for can be uppermost in the minds of professionals or not really relevant at all.

Despite the arbitrariness of case-by-case definitions, our entitlement as citizens to the care we need depends entirely on them. We are generally entitled to healthcare free according to our need and evidence-based medicine. There is no such entitlement to social care. This crucial difference was set in stone way back in 1946, with the National Health Service Act stipulating their needs were the same or had increased.7

On top of the issue of equity of access, standards of care that people do receive (and the extent to which they are truly personalised) are highly variable, ranging from excellent, through neglectful, to criminally cruel.

The added backdrop of massive cuts to public spending place Cinderella services under even more pressure. There has never been a better time for all four governments of the UK to take on the challenge of ensuring that care needs (those not defined as being healthcare) carry the same entitlement to free services as those that are defined as healthcare.

Though the underlying faultlines go back generations, the current social care funding crisis is pressing and very real. There is an ever-widening gap between the level of social care needed and funding allocated to provide it. This has a knock on effect on health that poses real risks to people with MS. A survey carried out by the Care & Support Alliance in 2011 found that a quarter (24 per cent) of disabled adults in England had already been affected by cuts to services – even though their needs were the same or had increased.7

Shockingly, almost nine out of 10 (88 per cent) GPs warn their patients are at risk because of insufficient social care support.8 This can only get worse as cash-strapped councils continue to raise the bar for access to services. In 2011-12, 83 per cent of councils set the threshold for eligibility for state-funded care at ‘substantial’, compared to 78 per cent in the previous year and 70 per cent in 2008/09.9

Our research shows the system of care and support is already failing to meet the needs of people with MS and the people who care for them.

Across the UK, budget cuts are squeezing the funds available for social care. At the same time, care costs are rising and an increasing number of older and disabled people require care and support. If this ever-growing gulf between the need for care and support and the funding to provide it is not addressed as a matter of urgency, services will reach crisis-point, with potentially devastating effects.

SOCIAL CARE AND PEOPLE WITH MS

Social care provides people with MS practical support to help them remain independent and lead a fuller life. This could include support with everyday tasks like washing and dressing, or getting out and about.

Although the majority (80 per cent) of people with MS say they did not need social care support in the past year, help provided by family and friends may mask demand for more formal support. Seven out of 10 (71 per cent) receive unpaid care, support or assistance from a friend of family member. There may be some misunderstanding of social care support, who is eligible and how to access it. Despite the fact that most did not believe they needed social care, nine out of 10 say they need at least occasional assistance from others.

When looking at unpaid carers, two themes emerge. First, those who have a carer are 11 per cent more likely to need social care but four per cent less likely to have that need met. Secondly, three quarters (76 per cent) of people who did receive social care support also had an unpaid carer, suggesting the social care support alone is not enough.

This supports what we already know – people with MS are supported by an army of unpaid, informal carers. We must ensure people can access social care and that those providing informal, unpaid care are properly supported.

MONEY MATTERS

Personal finances play an enormous part in people’s access to adequate social care support and our research reveals a stark divide. The people who are under the most financial strain are also the most likely to report a shortfall in the social care support they need.

Three out of four people worry about the financial burden of providing full-time care to a family member (76 per cent).10

Half of those really struggling to make ends meet say they do not receive the social care support they need. By contrast, nine out of 10 of people who are not financially comfortable get the social care they need.

It is reassuring that over the past 12 months, most (83%) of those with MS who rely on the government to pay for all their social care have seen no change in the level of support they receive. However, 53 per cent of those who bear the entire cost of social care themselves report having to pay more over the same period.

A similar picture emerges on access to equipment. Those most worried about their financial situation are the least likely to have access to a wheelchair, while those who are financially secure, are more likely to have access to a wheelchair.

Anne, from Warwickshire provides 24-7 care for her husband but asks: “Who cares for the carers? I went to the doctors feeling unwell and was told I had to be admitted to hospital immediately. When I asked, ‘who will look after my husband’, the doctor shrugged their shoulders and said ‘don’t know’. Our children do not live locally. My husband’s MS is complex and his needs are personal care and nursing care. If I have to go into hospital again, I want to know that he will be looked after properly.”

Tim Sudbury, aged 67, was diagnosed with MS around 25 years ago. His condition has now progressed to a stage where he cannot look after himself unaided, and his wife Marion is his full time carer. The couple receives a personal budget and 45 hours of care each week, but this is not enough and they’re struggling to cope with the cost.

Marion said: “I worry about our future, how we’re going to manage and what’s going to happen. Tim needs a great deal of support, but I need support too and I feel my needs are overlooked. The process of applying for more social care support, and appealing unfair decisions, is exhausting.”

Tim and Marion

MS services across the UK
Nearly three quarters of people with MS (71 per cent) have an unpaid carer. But of these, less than half (45 per cent) of those who needed one said that their carer had been offered a carers’ assessment – and our research reveals deep local and financial divides in provision of these important reviews.

**Our hope**

Looking ahead to the next 60 years, we want to see a world where every person with MS gets the social care they need, and provision does not depend on ability to pay.

**Our call**

We want governments across the UK to:

- Establish an entitlement to free care and support to meet needs arising from medical conditions, irrespective of age.
- Provide adequate funding for social care authorities to ensure people with MS really can access the services they need and retain financial security.
- Establish quality standards for social care similar to those used to drive up standards for healthcare. A key aspect of quality must be genuine shared decision-making in care planning.
- Ensure seamless support and integrated health and social care services for every person with MS. Fundamental to this is the inclusion of social care workers within multi-disciplinary teams.
- Ensure that preventative support for people with lower-level needs is built into the social care system.
- Offer carers’ assessments on a routine and consistent basis, regardless of whether the person with MS being cared for is in receipt of social care services. Assessment should always consider the carers’ needs for education and training as well as leisure and employment opportunities. Carers’ support services, like other areas of social care, then need to be made real, with a clear entitlement and funded services, including short breaks. Such services help the caring role to be sustainable and help carers to stay in work.
- Ensure prevention is a priority, with responsive and timely services for carers and people with MS to ensure situations do not spiral out of control.

**Our pledge**

We will:

- Improve our information and tools needed to equip and empower people with MS to secure the social care package which is right for them.
- Work with local government organisations to ensure services are responsive to people’s needs.
- Continue to invest in partnerships, such as the Disability Law Service, to increase access to legal services and advice for people with MS throughout the UK.
- Champion the crucial role of families, friends and work, in partnership with other carer-focused organisations, to increase support services.
Many people with MS can – and want – to work, but they face a series of social and physical barriers to getting and holding a job. Shockingly, only a quarter of those who are not in employment, but want to be, can access support to get a job.

It is therefore not surprising that only one in four people with MS who are of working age are employed, compared to three out of four of the wider UK population.

We also know that in two out of three cases, MS undermines employment and career opportunities and, on average, a person with the condition misses out on 18 years of working life.11

Helping people to stay in work, and so find new employment when they need to, is plainly beneficial to people with MS, employers and wider society. Staying in work helps to maintain normal life, engagement with others, a sense of purpose, being socially, mentally and physically active. Employers benefit from retaining experienced and valuable staff. Society benefits in so many ways, but not least the reduced costs that would be borne by the taxpayer resulting from people becoming unemployed.

A supportive employer can make all the difference to someone being able to stay in work. East Durham Homes – which looks after council housing – was nominated by employee Stuart Wood, who has MS, for the MS Society Awards in 2012. He says immense efforts have been made to enable him to continue doing his job and he’s had lots of support since being diagnosed. This has meant he’s been able to carry on working full-time.

Stuart says the company understands how unpredictable MS can be and is very flexible about letting him have time off if he has a relapse or hospital appointment. The firm has also helped with equipment and has supplied Stuart with an iPad since he found it difficult to write by hand.

“I am proud to work within a company that doesn’t see a person having a disability as an obstacle. They understand how important it is to me and my self esteem to keep working.

“This is a company that has actively taken it upon itself to learn and understand what multiple sclerosis is.”

Our research shows how the proportion of people with MS in work decreases with age.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Not in any form of employment</th>
<th>In employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 – 30</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>31 – 50</td>
<td>46%</td>
<td>54%</td>
</tr>
<tr>
<td>51 – 65</td>
<td>58%</td>
<td>42%</td>
</tr>
</tbody>
</table>

Support to find or stay in employment need met.

2008 – Employment and Support Allowance (ESA) replaces Incapacity Benefit (IB) and sees the introduction of a new test: The Work Capability Assessment (WCA) for all new claimants.

November 2011 – More than 23,000 people with MS who receive Incapacity Benefit still waiting to be reassessed.

April 2012 – People with MS who are placed in the Work Related Activity Group for ESA (requiring them to engage in some job-seeking activity) and those who receive contributory ESA have their benefits limited to 12 months.

From April 2013 – Personal Independence Payment, which for many will involve a face-to-face assessment, begins to replace Disability Living Allowance.

Last year the Welfare Reform Act was passed, introducing what David Cameron describes as: “The most ambitious, fundamental and radical changes to the welfare system since it was created.”

According to the recent MS Services across the UK report, in 2012: 33% of people with MS in employment; 42% of people with MS who receive Incapacity Benefit; 58% of people with MS who receive Incapacity Benefit.
We know from our experience of the Work Capability Assessment for ESA that people with MS often find these assessments extremely stressful, and there is clear evidence that stress can exacerbate MS.11

As MS is a chronic, long-term condition, with most people getting steadily worse, these face-to-face assessments are often unnecessary. 82 per cent of people who completed our research are on DLA, and, of these, 82 per cent are receiving both the care and mobility components. We expect around 46,000 working age people with MS to be reassessed for PIP.

Of people who receive DLA, 66 per cent need frequent or constant assistance from others – six times the number who do not receive DLA (10 per cent). Those who receive DLA are two times more likely to be struggling, or really struggling, financially – 18 per cent compared to nine per cent of those not in receipt of DLA.

This reveals a worrying interplay between income and need, with those who are more financially vulnerable, and have the greatest need for assistance, being the most reliant on DLA. Any loss or reduction in this support could be devastating.

There is also widespread concern that the debate surrounding these welfare reforms has resulted in a proliferation of myth, stereotype and prejudice towards those claiming benefits that are essential to their wellbeing.

FINANCIAL SECURITY UNLOCKS SERVICES

Our research reveals a clear link between financial security and care, and shows that people with MS who are struggling financially are in general less likely to receive the care and support they need.

For example, only 33 per cent of people who are really struggling financially and need emotional support are able to access it, compared to 72 per cent of those who are really comfortable. A similar trend is seen in access to information about MS and whether people who wanted to see a physiotherapist.

The most obvious explanation is that being financially comfortable provides the means to pay for care and support. But this has wider repercussions on physical and mental wellbeing, as can be seen on page 22 where we examine the impact of timely access to specialists.

Another worrying pattern emerges from the research – those under the greatest financial pressure are the most in need of care and support. There may be a number of factors at play:

• The impact MS has on employment.
• Increased day-to-day costs as a result of MS, such as having to take taxis.
• Having to pay for services such as physiotherapy, wheelchairs or home adaptations.
• The level of care available to someone on a lower income.
• There may also be a negative spiral, with inadequate care and services exacerbating MS and therefore increasing the level of assistance needed.

Our Call

We want governments across the UK to:

• Foster a better understanding of conditions such as MS among employers and support employees with MS to stay in work for as long as possible. Flexible working hours, scheduled work breaks with a place to rest, improved awareness of MS among colleagues and increased support from employers and colleagues may all assist a person with MS to remain in work.
• Protect investment in work-based support programmes.
• Ensure that multi-disciplinary health and social care teams include occupational therapists, who can do so much to help people with MS to stay active and help employers to make appropriate adjustments.
• Promote greater awareness of Access to Work and ensure workplace programmes challenge discrimination and meet the needs of people with MS.
• Ensure no one with a chronic, steadily worsening condition such as MS is subjected to unnecessary, stressful and costly reassessments for financial support.
• Ensure assessments for benefits such as ESA and PIP recognise the needs of people with fluctuating conditions such as MS.

Our Pledge

We will:

• Work to increase the number of local partnerships providing welfare and benefits advice.
• Continue to provide up to date information on changes to benefits, including a new ‘MS Essential’ publication about PIP in summer 2013.
• Work with the Disability Benefits Consortium to monitor the transition to PIP, including the performance of the two main providers, ATOS and Capita.
• Collaborate with the Work Foundation to explore how a pan-disability employers rating, which builds on the Positive about Disabled People Scheme, can be established.

Our Hope

Anyone with MS who wants to work should get the support they need to stay in employment. Accessing vital benefits should not be a struggle and welfare reform should not cause stress for people with MS. Income must not dictate access to vital services.

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A lottery of treatment and care – MS services across the UK

PHYSICAL AND MENTAL WELLBEING

A pound spent on prevention saves many more by reducing the cost of avoidable crisis care. There is also good evidence that being empowered, well informed and involved in your care enhances physical and mental wellbeing. However, this needs to be supported by access to a range of MS specialists who have the authority to coordinate care and treatment.

We have come a long way from the days of “doctor knows best”, to one where patient involvement, shared decision-making and self-management should be commonplace. Changes within professional bodies and shifts in government policy have led to improved access to information and greater patient involvement in decision-making – which are essential for self-management to work.

Shared decision-making brings other benefits. Research demonstrates that helping people to better care for themselves can lead to a positive impact on people’s clinical symptoms, improve physical and mental wellbeing and change how services are used. However, key to managing MS is the ability to see the right specialists when needed.

Self-referral schemes, which allow individuals to refer themselves directly to services without first seeing their GP, can help to achieve this. The ability of individuals to self-refer has been hugely successful in reducing the time to referral – particularly to physiotherapy, improving access to services and reducing costs associated with GP appointments. However, the ability to self-refer is only available in some areas and for some services. There should be a shared approach so that regardless of where people live they can access the services that they need when they need them.

While it is reassuring that people with MS have good access to MS specialist nurses and neurologists, and that there is little variation either between nations or by financial security, access to a specialist is not always timely. One in five people with MS rarely, or never, find it easy to see a healthcare professional when they need to.

The impact of this is costly in both human and financial terms. We know that timely access to specialists reduces hospital admissions and our work to protect specialist posts has identified significant costs associated with avoidable emergency care and re-admissions.

In local project work in Surrey, we found that more than £1 million was spent on emergency admissions for people with MS. The most common causes – urinary tract infections and pneumonia – should not require hospital treatment if managed appropriately with timely access to specialists.

Similarly, elsewhere £96,000 was spent treating urinary tract infections which could have been prevented through improved access to continence advice or a specialist nurse to fast-track treatment.

Figures from the National Audit Office, which cover emergency admissions in England, reveal a 32 per cent increase in neurology cases in the five years between 2005 and 2010 – almost twice the rise in admissions overall (17 per cent). There is no reason to believe these examples are not typical of the UK as a whole and clearly show the NHS could save millions of pounds spent on avoidable care by ensuring that people with MS are able to see the right specialists, at the right time.

The human cost, to often frail and vulnerable people, is incalculable.

ACCESS TO SPECIALISTS

A GLOOMY OUTLOOK

Around half of all people with MS experience depression, and a similar number suffer from anxiety. But our research shows that only half the people with MS (51 per cent) who need mood or emotional support actually get it.

Health professionals clearly play an important role in accessing these life-enhancing services. Eight out of 10 (78 per cent) of those who are always or usually asked what is important to them by professionals when helping to manage their MS could access mood or emotional support. But only four in 10 gain access to this support if the question is less frequently put. Access to a more proactive healthcare professional, who encourages people with MS to be involved in decision-making, clearly has a positive impact.

The same trend is seen for physiotherapists. Only 63 per cent of people who are really struggling financially had their need met to see a physiotherapist, in contrast to 76 per cent of those who are really comfortable.

ABILITY TO PAY

Access to physiotherapists, continence advisors and emotional support when needed.

For example, need met for emotional support:

<table>
<thead>
<tr>
<th>Mood and emotional support need met</th>
<th>Really comfortable</th>
<th>Comfortable</th>
<th>Neither comfortable or struggling</th>
<th>Struggling</th>
<th>Really struggling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Really comfortable</td>
<td>72%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortable</td>
<td>61%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither comfortable or struggling</td>
<td>48%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Struggling</td>
<td>41%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Really struggling</td>
<td>33%</td>
<td></td>
<td></td>
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</tbody>
</table>

A lottery of treatment and care – MS services across the UK

22 A lottery of treatment and care – MS services across the UK 23
ACTIVE MEASURES

At one time people with MS were advised to avoid exercise because of increased fatigue and heat sensitivity, which can worsen symptoms in the short-term.

But the balance of evidence has moved on and exercise is now recognised as important in helping people with MS to stay active. The evidence shows that exercise not only improves overall health, but also helps with mobility and muscle weakness, managing fatigue and generally staying physically and mentally well.

Physiotherapists play a vital role in enabling people with MS to remain physically active. Those with a physiotherapist are nearly twice as likely to have their need for support to remain physically active met, such as attending exercise classes (61 per cent vs 31 per cent).

Those who need more assistance from others are less likely to be able to see a physiotherapist if they need to. However, over half of those who need round-the-clock help want support to remain physically active. We believe there is a common misconception that people who need constant assistance do not need exercise classes. This clearly needs to be corrected.

The link between income and access to a physiotherapist suggests that being more financially secure ensures better access because it provides the means to pay privately for physiotherapy.

Northern Ireland out-performs the rest of the UK in providing support for people to stay physically active. In Northern Ireland, 57 per cent of people with MS say their needs met compared to 47 per cent in the UK as a whole.

In 2011, the MS Society launched a series of MS exercise classes in conjunction with Active Communities and Sport NI. The classes are designed to improve strength, mobility and balance with functional exercises. In 2012 we had over 1,600 attendances at 225 classes. We hope that such classes will now receive statutory support throughout Northern Ireland.

CONTINENCE ADVICE

Continence problems are a source of enormous stress and anxiety for people with MS. Accidents, or the fear of having one, impact on every aspect of everyday existence and have a corrosive effect on quality of life.

Trends for access to continence advisors mirror those for mood and emotional support and physiotherapists, and once again information opens the way. People who need, but don’t get, sufficient information about their MS are 21 per cent less likely to have seen a continence advisor when they needed to. A similar pattern emerges with attendance on self-management courses.

This may also influence access to new treatments. Last year, Botox was licensed for overactive bladder and access to a continence advisor would ensure people are aware of the treatment and how it may benefit them.

Linda Erskin, who has MS, said:
“The MS Society exercise classes have really helped me to get active and improve my strength and balance. Before the class started I found it difficult to go to the local gym, as most of the classes were too difficult to manage, but our class is tailored to the needs of people with MS.

It helps me to stay active, manage my MS symptoms and improve my general health.”

James West, aged 37, from Birmingham was diagnosed with MS in 2001.
In 2010 he began receiving Botox injections in his bladder wall to help with continence problems, and has been receiving the treatment ever since.

James said: “I’ve always had a really good relationship with my MS nurse, neurologist and other health professionals. I see them when I need to; their help has been invaluable in the day to day management of the condition, especially with more distressing symptoms – like bladder management.”

KNOCKNOWLEDGE EMPowers PATIENTS

Nine out of 10 people with MS who always find it easy to access healthcare professionals also report receiving sufficient information about their condition, compared to only four in 10 of those who never find it easy to see a professional. However, there is an element of chicken-and-egg: Do specialists provide, or signpost, this information? Or are those who are better informed more likely to access a specialist?

Fay Lovell is 39 and lives in the West Midlands with her husband and their two daughters. Fay was diagnosed with relapsing remitting MS in 2000, but has rarely seen an MS nurse or neurologist since then and, as such, has never taken disease modifying treatments for her condition.

She said: “I do feel I have been overlooked by the medical profession. When I was diagnosed I was sent away with little information, and I thought I just had to get on with it. I saw my GP when symptoms got really bad, but I never knew there was an MS nurse or other services out there to help me. I only realised what I was missing when I started going online and meeting others with the condition.”

Having the opportunity to attend a self-management course is also linked to feeling informed about MS; 85 per cent of those who had the opportunity to attend a course got all the information they need about MS, in contrast to only 63 per cent of those who did not. Similarly, while courses provide information about MS, people who are more informed about their MS may also be more aware of the existence of these courses.
In Scotland, people with MS have much better access to self-management courses and their experience provides a blueprint for improving access elsewhere. The Scotland Self-Management Fund was launched in 2009, providing financial support for voluntary and community health organisations and groups to deliver sustainable and innovative approaches to self-management. MS Society Scotland is a key provider of self-management courses, with 141 people attending courses in 2012 alone.

**SPEND TO SAVE**

Austerity and cuts are having an impact on all levels of government, but these findings suggest that targeted spending and patient involvement are not only cost-effective, but could save the NHS millions of pounds in unnecessary hospital admissions.

Our research suggests that those who are more actively involved in their healthcare (ideally working with professionals to plan care) are more likely to access services. Improving access to these specialists could prevent unnecessary hospital admissions.

**OUR HOPE**

We believe that people with MS should be empowered, involved in their care and well informed. This is key to their physical and mental wellbeing. We want to see an end to the postcode lottery of access to specialists and the worrying inequality of access linked to income.

**OUR CALL**

We want governments across the UK to:

- Incentivise NHS organisations/providers to offer a local self-referral service that will ensure people with MS have timely access to any member of the multi-disciplinary team, including MS specialists, at the point of need and enable them to self-manage their condition.
- Ensure MS specialists are involved in the planning of all health and social care services for MS.

**OUR PLEDGE**

We will:

- Work to improve understanding of MS among all health and social care professionals.
- Embed a culture of “no decision about me without me” in our information and support volunteer programme so that health and social care professionals are prompted by people with MS to understand what matters the most to them when managing their MS.
- Ensure our fatigue management and cognitive behavioural training courses are rolled out across the UK to enable health and social care professionals to better support people with MS to manage fatigue and tackle feelings of low mood.
- Provide information for people with MS to boost understanding of the value of exercise.
- Work in partnership with health and social care professionals to support people with MS to remain active.
- Continue to promote and protect the role of MS specialists at a national and local level.

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NEXT STEPS

Over the past 60 years, new treatments have emerged that not only help treat the debilitating and often hidden symptoms of MS, but also modify the course of the condition. These therapies can be transformative for people living with the anxiety and uncertainty of an unpredictable, fluctuating condition such as MS. Given the life-changing potential of these medicines, it is shameful that access is so abysmally low across most of the UK.

It is deeply depressing to see how so few people with MS who are eligible for disease-modifying and symptom relief treatments benefit from these therapies. Living with MS is a battle without having to fight for the effective licensed treatment options which, by law, should be made available on the NHS. However, access to medicines alone will not enable people with MS to enjoy full and active lives; excellent access to a broad range of health services and care and support services is also vital. Yet in these areas our research reveals shocking inequality.

Those who are struggling the most financially are the least likely to be able to access a range of support services, despite being the most likely to need this help. This is seen in access to physiotherapy, mood and emotional support and social care and support. And while people with MS report having access to a range of MS specialists, it isn’t always easy for people to see them. This has serious implications because we know that timely access to the right care and support can prevent hospital admissions and deliver significant savings to the NHS. These health inequalities are unacceptable; people with MS should be able to access the right care, when they need it – regardless of income.

Our findings must be seen against the backdrop of a care and support system which fails both those with MS and the people who care for them: the challenging economic climate and the well-founded fears people with MS have about losing their benefits as a result of assessments that do not properly recognise the hidden and fluctuating nature of the condition.

The MS Society has been working hard to tackle many of these issues. We will continue to do that and always look for ways that we can make the most impact for people. Now is the time though for all tiers of government, across the UK, to step up to the mark and make lasting and positive change. They must:

- Ensure every person with MS has a personalised treatment, care and support plan, with at least two comprehensive reviews each year. These multi-disciplinary reviews should be led by an MS specialist who can ensure treatment options are reviewed on an ongoing basis; that individuals have access to information to help them make informed choices; and so they can be referred to relevant health and social care services that meet their needs. These reviews should occur regardless of whether a person is on treatment and should be in addition to other appointments made at the point of need, for example, experience of a relapse or a significant change in symptoms.
- The care and support available must be seamless and responsive; integrating health, care and support services, with a common approach to quality and shared decision-making. Access must be based on need rather than ability to pay.
- Ensure assessments for benefits such as ESA and PIP recognise the needs of people with fluctuating conditions such as MS. This should take into account the chronic, steadily worsening nature of the condition and people with MS should not be forced to submit to unnecessarily stressful and costly reassessments.
- Ensure carers are routinely and consistently provided with a comprehensive carers’ assessment, regardless of whether or not the person they care for receives social care services. They should be supported by services which are provided in a timely and responsive manner.

Implementation of these four core recommendations will vastly improve quality of life for people living with MS and their carers by ensuring:

- People with MS have regular and timely access to a range of MS specialists throughout their lives, providing specialist input, information and referral to relevant services when it is needed most. This would help ensure people with MS are fully informed and empowered to discuss a range of issues that may be of concern, including new symptoms, how these can be managed, and treatment options.
- Care and support is available at the right time to enable people with MS to live as independently as possible.
- People with MS are supported to manage the extra costs of living with a disability and are able to receive the benefits to which they are entitled, whether they are in employment or not.
- Friends and family members who care for a person with MS feel supported. Pending a carers’ assessment, they will be able to access local services to ensure their decision to care for someone does not compromise their own health wellbeing and ability to enjoy a full and active life.

Government commitment to these recommendations will help make the difference between MS being a condition that destroys lives and supporting people with MS to enjoy the full and rich lives to which they are entitled.

It is our sincere hope that advances in medical science, comprehensive care packages, a more sophisticated benefits system and greater understanding from employers will enable the majority of people affected by MS – and their carers – to enjoy full and active lives.

Together we will beat MS. Thank you for your support.

“it is imperative that each of us voice our concerns, because, when all said and done, we are the ones with MS and we know what we need – the Campaigns Community connects people and allows them to become a strong, united voice to begin tackling the common issues we all face.” – Campaigns Community member, 2012

Are you as impassioned about some of these findings as we are? Then consider how you might play a part in helping to hold our governments across the UK to account and join our large online community of campaigners at the address below. Here you can stay updated about our campaigns work, learn how government policies might affect people with MS and learn how you can get involved in our campaigns work. Once here, you can also check out our new range of campaigns guides, including a guide on how to campaign for access to MS medicines, functional electrical stimulation and a local campaigners’ toolkit.

www.mssociety.org.uk/campaignscommunity

A lottery of treatment and care – MS services across the UK
WHAT MUST BE DONE

OUR CALL – WE WANT GOVERNMENTS ACROSS THE UK TO:

1. Ensure every person with MS has a personalised treatment, care and support plan, with two comprehensive reviews each year. These reviews should be led by an MS specialist who can ensure that treatment options are reviewed on an ongoing basis; that individuals have access to information to help them make informed choices; and so they can be referred to the health and social care services required to meet their needs. These reviews should occur regardless of whether a person is on treatment and should be in addition to other appointments made at the point of need, for example, experience of a relapse or a significant change in symptoms.

2. The reviews need the backing of systematic, integrated commissioning, so that coordinated, multi-disciplinary care becomes a reality.

3. The Association of British Neurologists (ABN) should build on their established professional leadership and update the 2009 prescribing guidelines for MS. These prescribing guidelines should be updated after the publication of any further guidance (by statutory regulators) on new treatments.

4. Local health authorities must avoid blanket bans on approved medicines and make recommendations on a case-by-case basis according to individual needs and circumstances. In so doing they should respect the decisions made by the MHRA and EMA on the safety and efficacy of treatments.

5. Establish an entitlement to free care and support to meet needs arising from medical conditions, irrespective of age.

6. Provide adequate funding for social care authorities to ensure people with MS really can access the services they need and retain financial security.

7. Establish quality standards for social care similar to those used to drive up standards for healthcare. A key aspect of quality must be genuine shared decision-making in care planning.

8. Ensure seamless support and integrated health and social care services for every person with MS. Fundamental to this is the inclusion of social care workers within multi-disciplinary teams.

9. Ensure that preventative support for people with lower level needs is built into the social care system.

10. Offer carers’ assessments on a routine and consistent basis, regardless of whether the person with MS being cared for is in receipt of social care services. Assessment should always consider the carers’ needs for education and training as well as leisure and employment opportunities. Carers’ support services, like other areas of social care, then need to be made real, with a clear entitlement and funded services, including short breaks. Such services help the caring role to be sustainable and help carers to stay in work.

11. Ensure prevention is a priority, with responsive and timely services for carers and people with MS to ensure situations do not spiral out of control.

12. Foster a better understanding of conditions such as MS among employers and support employees with MS to stay in work for as long as possible. Flexible working hours, scheduled work breaks with a place to rest, improved awareness of MS among colleagues and increased support from employers and colleagues may all assist a person with MS to remain in work.

13. Protect investment in work-based support programmes.

14. Ensure that multi-disciplinary health and social care teams include occupational therapists, who can do so much to help people with MS to stay active and help employers to make appropriate adjustments.

15. Promote greater awareness of Access to Work and ensure workplace programmes challenge discrimination and meet the needs of people with MS.

16. Ensure no one with a chronic, steadily worsening condition such as MS is subjected to unnecessary, stressful and costly reassessments for financial support.

17. Ensure assessments for benefits such as ESA and PIP recognise the needs of people with fluctuating conditions such as MS.

18. Incentivise NHS organisations/providers to offer a local self-referral service that will ensure people with MS have timely access to any member of the multi-disciplinary team, including MS specialists, at the point of need and enable them to self-manage their condition.

19. Ensure MS specialists are involved in the planning of all health and social care services for MS.
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The following organisations endorse our UK analysis and recommendations:

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