

# Is MS care fair?

Key findings from the MS Trust's survey  
into the experiences of people living with MS



# Too many people living with progressive MS feel they are getting a second class service

That's the overwhelming message we heard from the MS Trust's survey of almost 2,000 people living with MS, conducted in February and March this year.

We found that people with progressive MS, who make up almost half of the total MS population in the UK, are seeing their key specialist health professionals far less often than people with relapsing remitting MS, and often failing to receive the proactive, continuing care that can make all the difference to living well with the disease.

We also found that some people diagnosed with secondary progressive MS feel abandoned and left to manage on their own, just as their disease is entering a new phase, with complex symptoms and increasing disability.

What's more, even people who feel that they currently receive excellent care from their MS team feel pessimistic about the future, as they see pressure increasing on specialist services.

These findings give us a vivid picture of how people with MS feel about the state of MS services today. They show the vital difference that specialist health professionals can make for people living with MS – but also tell us that many people feel they are missing out.

These findings demonstrate the urgent need for new thinking on ensuring equity in MS services. We need to assess the challenges facing MS teams, and develop new ways of delivering services that work for everyone living with MS, no matter what type of the disease they have.

This is a conversation the MS Trust is now leading with our MS Forward View project, working with MS specialist health professionals, commissioners, managers and people with MS themselves. Find out more about this project and how you can support our work to make MS care fair on p7.

**Amy Bowen**  
Director of Service Development, MS Trust

## About our survey

In February and March 2016 we invited people with MS to complete a short survey telling us about their experience of MS care. We asked what type of MS they had, which health professionals they saw, and how often they saw them. We asked if their care had changed, if and when their disease progressed, and whether there were services they felt could help them but which they couldn't currently access.

1,857 people with MS from across the UK completed our survey. Their demographics were broadly representative of what we know of the UK's 100,000 MS population. 50 per cent said they had relapsing remitting MS (RRMS), 29 per cent had secondary progressive MS (SPMS) and 16 per cent had primary progressive MS (PPMS).

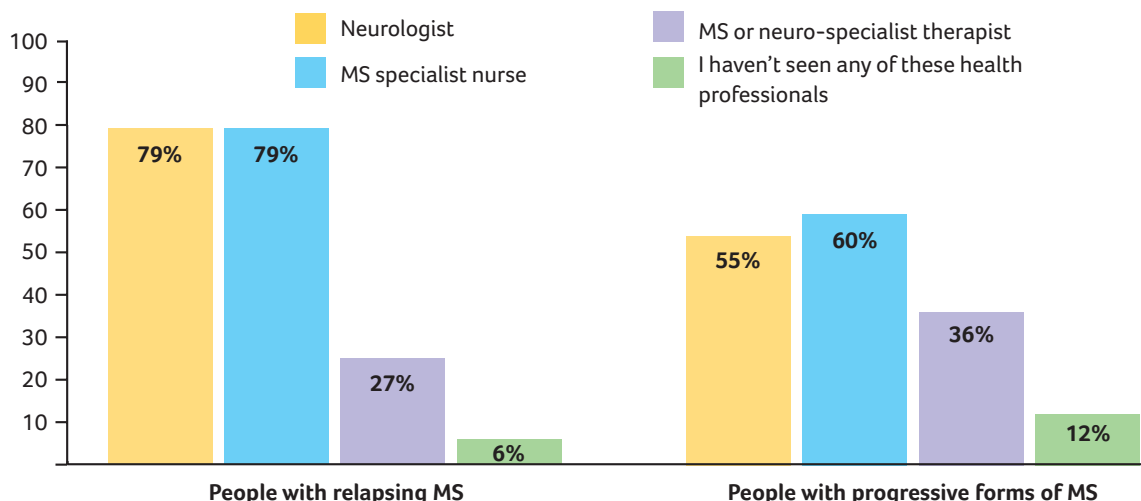
From our work with MS nurses, the MS Trust has a wealth of data on people benefiting from specialist services. This survey gives us a new insight into the experience of people who feel they have lost touch, or never been in contact with, this vital support.



## KEY FINDINGS

# 1) People with progressive MS get less time with their MS specialists

**Q: During the past year, have you had a face-to-face consultation with any of the following about your MS?**



**Our survey makes plain what many people have long suspected: people with progressive MS are, on average, seeing their MS specialists much less often than people with relapsing remitting MS. Worryingly, 12 per cent of people with progressive MS hadn't seen any kind of specialist health professional in the last year. This falls a long way short of NICE's MS Quality Standard, which recommends that all adults with MS are offered a comprehensive review at least once a year by a specialist health professional.**

### What does this mean?

MS specialist services are facing complex challenges. MS Trust research has shown that we don't have enough MS specialist nurses in the UK, and that many of the nurses in post are managing unsustainable caseloads.

In addition to the strain this shortfall puts on services, we are seeing an increase in the numbers of people with RRMS taking disease modifying drugs (DMDs).

This is to be welcomed: there is increasing evidence that early, proactive use of a DMD

can help people with MS to stay healthy for longer.

However, all DMDs, and particularly some of the newer drugs, require extensive monitoring, which puts great pressure on nurse time.

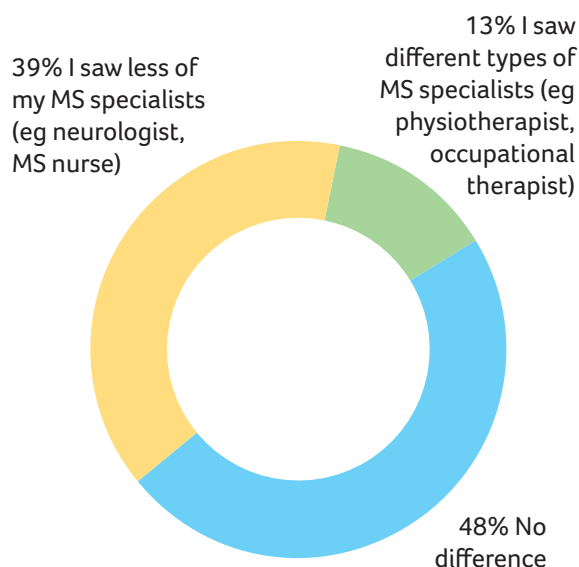
The MS Trust knows that MS specialist nurses are concerned that the commitments around increasing DMD use will leave them with less time to help people with progressive MS. There are currently no DMDs for people with progressive MS. They often have complex needs that require the support of a co-ordinated team of specialist health professionals.

We know that ongoing proactive care from MS specialists helps avoid crises, need less emergency care and stay independent for longer.

The MS Trust wants to make sure no one misses out on specialist care. Our new project, MS Forward View, has been set up to look at how we make sure MS care works for everyone. Find out more on p7.

## 2) Many people with secondary progressive MS feel abandoned and left to manage alone

**Q: If you have secondary progressive MS, what changes did you notice in your access to care when your disease entered the progressive phase?**



**39% of people with secondary progressive MS told that they saw less of their MS specialists once their disease became progressive. They were receiving less input from specialist health professionals, just as their needs were becoming more complex and they began to experience new, often severe symptoms.**

### What does this mean?

The experiences of people with secondary progressive MS are interesting as they often have a dual perspective on MS services. They might have been taking a DMD, and having regular meetings with their neurologist and MS specialist nurse. They may then have been advised that their MS was progressing, and that the DMD may no longer be effective.

Ideally they would be able to continue to receive the support of their MS nurse and also access a range of therapists (including physios, OTs, continence nurses, speech therapists and neuropsychologists, for example) who could help them find ways to manage their symptoms.

However, a worrying trend in our survey

### Selected comments

All of a sudden you get a feeling that you're no longer on the radar and that, in some respect, you've been abandoned by those that were previously involved with you.

There is no treatment for people with progressive MS, but little awareness that, because of this, we need *more*, not less, intervention from healthcare professionals.

When I had relapsing remitting MS I was under the care of a neurologist and MS specialist nurse and took a DMD. Now that I am secondary progressive, I have been discharged from that care and referred to my GP – nothing else has been offered.

In my opinion once you are diagnosed with secondary progressive MS you are pretty much left to get on with it.

results was the experience of people with MS being effectively 'discharged' from the care of their neurologist and even their specialist nurse.

While it might be appropriate for some people with progressive MS to see less of their neurologist, it is important that they continue to receive the support of their MS specialist nurse and relevant therapists.

A significant number of respondents told us that when their MS became secondary progressive, they felt were left to manage on their own, with the support of their GP.

While some GPs provide excellent support to people with MS, statistically GPs are likely to have little experience of MS and can in no way be a substitute for a specialist health professional.

It is vitally important that we address the needs of people with progressive MS, and make sure that they receive continuing, specialist care. In our MS Forward View project we're looking at innovative ways that MS teams can work together to provide ongoing, holistic care – see p7.



## KEY FINDINGS

### 3) People with MS feel they can't access the services they need

**Q: Are there NHS services that you think would help you, that you haven't been able to access in the past year? If so, which ones?**

Physiotherapy outside of crisis moments, i.e. 'maintenance'. Would not need to be often. But round here, it's a block of 6 or 8 weeks then back on the waiting list until the next acute moment.

Access to the neuropsychologist regarding my memory problems. Currently a 16 week wait before I can be considered for an appointment and no time frame of how long after that before I would see him.

Better access to continence support. It took me 18 months of nagging my GP to get a special prescription approved by my local commissioning group for a bowel irrigation system.

From initial query to face-to-face appointment for an FES device to help with my foot-drop has taken 6 months. Too long when keeping disability at bay is a priority.

Self-referral for podiatry, psychology support and massage would have been beneficial. I have paid for these services but not everyone can afford to.

Physiotherapy dedicated to people with MS on a regular hands-on basis. It's not enough to be given a list of exercises. It's hard to be motivated when you have MS fatigue.

#### What does this mean?

Many respondents told us how impressed they had been with the care they received. MS specialist nurses were frequently singled out for special praise.

However, many people with MS had clearly identified which services they felt could help them, but felt frustrated that they were unable to access them. The need for access

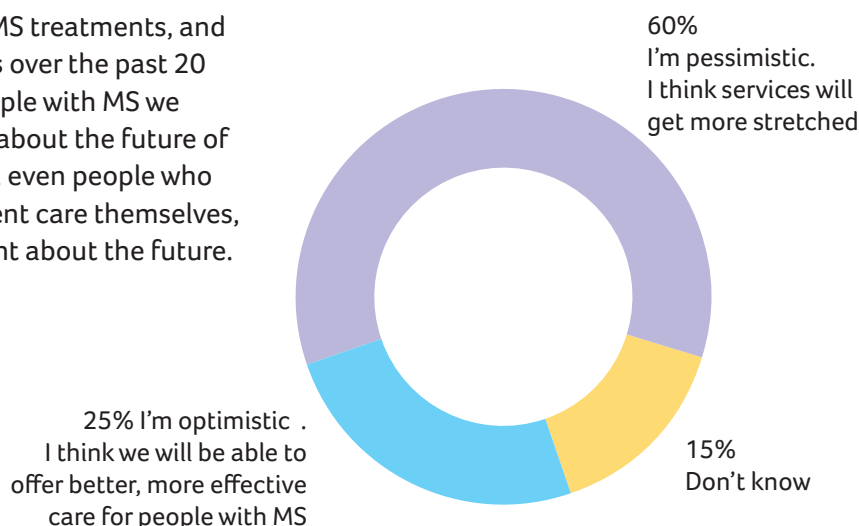
to ongoing physiotherapy in particular, rather than a short intervention programme, was a recurring theme.

The need to develop effective multidisciplinary MS specialist teams is a key element in our MS Forward View project.

The MS Trust is also working closely with other charities to map, develop and promote the work of specialist neurological therapists.

### 4) People with MS feel pessimistic about the future of their care

Despite the advances in MS treatments, and the growth of MS services over the past 20 years, the majority of people with MS we surveyed felt pessimistic about the future of MS services. Significantly, even people who reported receiving excellent care themselves, frequently felt unconfident about the future.



# About MS and MS specialist services

Multiple sclerosis (MS) is a neurological condition that affects the nerves in the brain and spinal cord (the central nervous system). It's a lifelong condition and affects over **100,000 people in the UK**. It affects almost three times as many women as men.

**Most people are diagnosed in their 20s and 30s** but it can be diagnosed in younger and older people. There is a wide range of possible symptoms including fatigue, pain, vision problems, walking difficulties, numbness, pins and needles and burning sensations, cognitive problems, continence issues, depression, sexual difficulties, speech and swallowing difficulties, spasticity and tremors. Symptoms can come and go throughout the course of the disease. Some symptoms, such as neuropathic pain, can be very difficult to treat.

The range of symptoms and disabilities caused by MS, and the unpredictable course of the disease, make it particularly complex and challenging to manage.

There are three main types of MS.

85% of people diagnosed have **relapsing remitting MS (RRMS)** at onset. When experiencing a relapse, people with MS can become very unwell for a period of days, weeks or months.

They may recover completely, but around half of relapses leave some form of residual disability. Many people with relapsing remitting MS are treated with disease modifying drugs (DMDs). These are typically started soon after diagnosis to reduce the severity and frequency of relapses, and they may reduce disability.

Relapsing remitting MS may transition into **secondary progressive MS (SPMS)**, where there is a sustained increase of disability, independent of relapses. Around 58% of people with RRMS will develop SPMS 15–20 years after diagnosis.

10–15% of people with MS are diagnosed with **primary progressive MS (PPMS)**, where symptoms get progressively worse over time from the outset, rather than appearing as relapses. There are currently no disease modifying drugs that work in PPMS and none have any effect on the gradual accumulation of disability in SPMS. Those people who develop advanced MS may need to use a wheelchair or stay in bed,

may require help eating, have severe cognitive difficulties and significant speech problems.

We estimate that current MS population of the UK comprises approximately 50% people with RRMS and 50% people with progressive forms of MS.

Only a **neurologist** can give a definite diagnosis of MS. Many people who are diagnosed by a general neurologist then transfer to the care of an MS specialist neurologist. We believe everyone with MS should be able to access an MS specialist neurologist.

**MS specialist nurses** play a vital expert role in assessing problems, providing treatments and advice and coordinating care for people with MS. We believe that everyone with MS should have regular, continuing access to an MS specialist nurse, from the moment they are diagnosed.

But the quality of care for people with MS is also dependent on the availability of a team around the specialist nurse who have expertise in MS.

We believe that people with MS should be able to access the specialist expertise of a whole range of **allied health professionals**, including, but not limited to, physiotherapists, occupational therapists, speech and language therapists, orthoptists, psychologists, continence specialists and rehabilitation physicians at different times to assess and treat their symptoms effectively, and to prevent secondary complications from developing as a result.

However, we know that, across the UK, there are **gaps in services**, and many MS teams are overstretched. Many MS specialist nurses have **unsustainable caseloads**. We also know that MS services face new challenges.

There is a growing consensus that the goal of MS care should be to maximise **lifelong brain health**. This strategy includes early intervention with a DMD for people with RRMS, a clear treatment target and regular monitoring – all of which will be challenging for MS services as they are today.

It also means the adoption by people with MS of a '**brain-healthy**' lifestyle, including activities that promote the growth of cognitive reserve, a healthy diet, exercise, not smoking and management of other health conditions.

# About MS Forward View

The MS Trust is committed to helping develop specialist services which enable everyone affected by MS to access the best possible care. MS Forward View is part of our project to make this vision a practical and workable reality.

Throughout 2016 the MS Trust is bringing together clinicians, specialised and local commissioners, professional bodies, experts in service planning, multidisciplinary educators, people with MS and patient organisations, to produce an action plan to improve and measure access to care. This plan will also help define future education programmes for MS specialists.

By addressing the increasing demand on MS services and the effects of new treatment paradigms, the project will identify the key actions needed across the MS sector to enable services to deliver efficient, effective and accessible services for everyone with MS.

During this one year project, we are

- describing the barriers and enablers to accessible care, including the impact of NHS funding systems in England
- identifying key points along the MS care pathway where there is greatest opportunity to improve services
- exploring the opportunity to improve care by using existing staff, skills and resources in new and different ways
- describing and mapping current provision of MS services across the UK
- looking at ways of measuring the quality and equity of MS services to contribute to further work on standards of MS care
- defining future projects and education programmes to test and evaluate new ways of working to improve care

This is a hugely ambitious project. We rely on donations to continue our vital work. To find out more and to find out how you could get involved visit [mstrust.org.uk/care](http://mstrust.org.uk/care)

## The MS Trust believes

Everyone newly diagnosed with MS should have an holistic assessment from an MS specialist nurse, and be offered appropriate information and support.

Everyone with MS should have continuing access to an MS specialist nurse from diagnosis, and have a comprehensive specialist review every year.

Everyone with MS should have access to neuro-specialist allied health professionals such as physiotherapists and occupational therapists, when they need them.

Everyone with MS should be able to meet their MS specialist in the place that's most appropriate for them – for some, this might be at home.

Everyone with MS should be able to contact their MS specialist service and receive a response within 2-3 working days – sooner if they are experiencing worsening symptoms.

Everyone with MS should be offered education and information on living well with MS and managing symptoms such as fatigue.



LET'S MAKE  
MS CARE

FAIR

Find out more and get involved  
[mstrust.org.uk/care](http://mstrust.org.uk/care)

# About the MS Trust

The MS Trust is a charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We produce practical, reliable information, online and in print, and offer a telephone and email enquiry service to anyone who needs to know more about MS.

We work to make sure everyone affected by MS can access good quality, specialist care.

We offer a full range of support to both specialists and health professionals with an interest in MS, including online information, publications, newsletters and professional development.

We work in partnership with health professionals to improve MS services now and in the future.

We rely on donations to fund our vital services.

To find out more about our work, how we can help you and how you can get involved

- visit **[mstrust.org.uk](http://mstrust.org.uk)**
- call **01462 476700**
- or email **[info@mstrust.org.uk](mailto:info@mstrust.org.uk)**



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