



Multiple Sclerosis Society



Together to beat MS

Our strategy 2015 to 2019

More than 100,000 people in the UK have multiple sclerosis, and many hundreds of thousands more have a friend or family member with the condition. Every one of them shares the uncertainty of life with MS.

MS attacks at random and many of the symptoms are invisible to others. Symptoms usually start in your 20s or 30s and diagnosis can be scary and heartbreaking. MS can get steadily worse, or remain unpredictable throughout your life – one day you can be fine, the next you might lose your sight or be unable to move.

The MS Society is the leading UK charity for people affected by MS. We're fighting to improve treatment and care to help people with MS take control of their lives. And with your support, we're funding research to help us beat MS for good.

Our vision

A world free from the effects of MS.

Our mission

To enable everyone affected by MS to live life to their full potential and secure the care and support they need, until we ultimately find a cure.



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Foreword

Whoever you are, you're reading this because you care about MS.

Whether you have MS or know someone as a family member, friend, colleague or patient, you have an important part to play in beating MS.

None of us can do it alone. We can only do it together. And it is this collaborative, united approach that is at the heart of the MS Society's 2015 to 2019 strategy.

Michelle Mitchell, our chief executive and Hilary Sears, our chairman, explain more on pages 4-5.



A remarkable history

Since the MS Society was founded in 1953, we've seen, and been part of, some remarkable developments that have led to big improvements in the quality of life of people living with MS.

Our understanding of MS has increased dramatically through biomedical research; as has our understanding of the treatments and interventions that can positively change someone's experience of living with the condition. Diagnosis – while still sometimes a long and difficult process – is now quicker for most. And people with relapsing remitting MS today have far more treatment options than just five years ago.

Sadly, for those with progressive MS, there remain only treatments that can help manage symptoms rather than alter the course of the condition – and even these can be hard to access.

A growing movement

There is still much to do, but as our understanding of MS has grown, so too has the number of people who have joined our cause. We have a huge network of thousands of dedicated volunteers across the UK in a wide range of roles – from providing invaluable support and information to people affected by MS, to helping us campaign or decide which research projects to fund.

There are thousands more who generously and regularly donate or fundraise to help us fund world-class research and continue to provide support and information to those who need it.

And there are many more who actively participate in our events, online forums and support groups – providing invaluable peer-to-peer support and friendship in the way only someone who has been there can.

**It is this
community
that makes
us strong.**



Your strategy

Although people with MS, their families and carers benefit from our work, they are also integral to designing and delivering it. That's why, when we began to develop a new strategy to guide our plans from 2015 to 2019, we started by asking people affected by MS (as well as our volunteers and staff) what was important to them. Over 3,000 people contributed.

This process helped us identify the seven organisational goals that underpin our strategy, and the objectives that will help us achieve these goals.

The goals are presented in order of priority. We know that the very top priority for people with MS is the development of (and access to) effective treatments, including those that can slow, stop or reverse the accumulation of disability. That is not to say the other goals are not important; they absolutely are.

We need you

Our new strategy is evolutionary, not revolutionary. It continues in many ways what we have always done and what we stand for. We'll continue to fund innovative MS research, influence the development of high-quality services and support,



and bring the MS community together locally, nationally and virtually. But we have identified ways in which we can work more effectively in these areas, to achieve the goals people affected by MS have told us they want us to focus on.

Of course, we can't achieve these goals alone. We need help and support from our community, and everyone who wants to end MS.

Together, we can beat MS. Please help make our vision a reality.

Our approach

Several common themes run throughout our work to support people living with MS.

These themes guide what we do, how we work, and the decisions we make.



Working alongside people affected by MS

People affected by MS are at the heart of our decisions and work. However, we know we can do much more to become an organisation of, not just for, people affected by MS. We'll involve people affected by MS in all areas of our work, and take full advantage of their insight, experience and knowledge.

Working with other organisations

We know we can't achieve everything by ourselves. Working alongside other MS charities, professionals, service providers, government departments and organisations across the MS, neurology and disability sectors will be crucial if, together, we are to make real progress towards our goals.

Focusing on areas where we can have the greatest impact

Our resources are finite. We'll prioritise our work to ensure the best and most effective use of resources; and we'll be clear and explicit about our role and what we expect of others.

Understanding what we want to achieve

Having a clear understanding of the outcomes we want to achieve and the progress we're making is fundamental to our success. So developing better ways to measure our impact is one of our first tasks.

Reaching out to everyone affected by MS

We exist to support everyone affected by MS. Yet we know that, although our work reaches and supports large numbers of people, there are others we don't always reach. We'll make sure our work is inclusive, and actively work to reach and engage with all individuals and communities.

Tailoring our approach

There's so much we can learn and achieve by working collaboratively across the world. And there are other contexts in which a UK-wide, nation-specific, or local approach will be necessary. Whatever the context, we'll continue to be a UK-wide organisation working to achieve common goals.

Our goals

These goals will underpin all our work from 2015 to 2019. They are ordered according to the priorities of people with MS.



1 Effective treatments

People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability.



3 Preventing MS

Progress in research means that fewer people will develop MS.



2 Responsive care and support

People with MS, including those being diagnosed, will have access to support that is responsive to their needs, and recognises them as equal partners in their care.



4 Quality information

People affected by MS will have access to high-quality information that meets their needs.



6 Supporting families and carers

The families and carers of people with MS will have access to the support they need.



5 A strong community, independent lives

People affected by MS will be able to live their lives, strengthened by a community that ensures no one has to face MS alone.



7 Greater certainty about the future

People with MS will have greater certainty about how their condition will progress.

GOAL 1



Effective treatments

People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability.

Effective treatments

We know that access to effective treatments is the top priority for people with MS. Although significant progress has been made in developing treatments for relapsing remitting MS, there are still no effective treatments for people with progressive MS that can alter the course of their condition, although some symptom management therapies are available.

Over the next five years we'll double our investment in research – accelerating progress into finding new treatments. We'll also use our influence, internationally, nationally and locally, to improve access to the treatments that do exist.

Our five year objectives

- We will have increased the proportion of people with MS who have timely access to the medicines and treatments which are right for them. This will include improved availability of treatments, access to informed clinicians, and provision of information and support to help people with MS make the right decision for them.
- We will have improved our understanding of fatigue, including how to measure it more accurately, supporting the development and evaluation of future treatments.
- We will have a better understanding of the long-term impact of people with relapsing remitting MS receiving aggressive treatments early on in the condition.
- We will have identified several new targets with myelin repair potential, some of which will be in small-scale clinical trials. A clinical trial of bexarotene (a potential myelin repair drug) will be complete, informing future work.
- Preparatory work required for a large-scale rolling, adaptive clinical trial for potential treatments for progression in MS will have been commissioned and completed, and the trial itself will have begun.
- A small-scale trial on vitamin D as a potential disease modifying treatment in people with MS will be nearing completion, and will inform the design of larger-scale trials.



Karen has MS and is a member of our Research Network. She helps shape our research programme by ensuring the research we fund reflects the needs and priorities of people affected by MS, and that it gives hope for the future.



Responsive care and support

People with MS, including those being diagnosed, will have access to support that is responsive to their needs, and recognises them as equal partners in their care.

Responsive care and support

It's essential that people with MS have timely access to relevant professionals, who are informed about MS and the options available, but who also recognise that people with MS should be at the centre of decisions. We want to ensure that everyone with MS, wherever they live and whatever their circumstances, gets the responsive and person-centred support they need.

Our five year objectives

- We will have increased access to person-centred, coordinated and responsive health and social care that recognises people with MS as equal partners in their care, including access to appropriate professionals and specialists.
- We will have increased the ability of people with MS to be physically active in a way which is appropriate for them.
- People affected by MS will have improved emotional and psychological wellbeing.
- We will have selected, adapted or developed a promising self-management programme for people with MS, and a clinical trial programme will have begun.

Sanjay is a long-standing volunteer and former trustee of the MS Society, and co-founded the Asian MS national support group in 1997. He campaigns for responsive care and support that recognises all of him, not just his MS.





Preventing MS

Progress in research means that fewer people will develop MS.



Preventing MS

We're much closer to understanding what causes MS than we were 10 years ago. We know MS is caused by a combination of genetic and environmental factors, but there's still a lot to learn about the different risk factors and how they interact with each other to lead to someone developing the condition.

Continuing scientific research to increase our understanding of what causes MS is vital; it's the only way we'll be able to prevent the condition in the future. By investing more in research, we'll create real progress towards future breakthroughs that could mean a world without MS.

Our five year objectives

- We will have a better understanding of the causes and risk factors involved in MS, and how they fit together.
- We will understand what a trial of an intervention to prevent MS might look like, including the time and resources required to run a prevention trial.

Charlotte helps us raise awareness of MS through sharing her family's experience of living with the condition. Finding a way to prevent MS is really important to Charlotte so that future generations don't have to go through what she does.



GOAL 4



Quality information

People affected by MS will have access to high-quality information that meets their needs.



E



A strong community, independent lives

People affected by MS will be able to live their lives, strengthened by a community that ensures no one has to face MS alone.

A strong community, independent lives

Life can be tough. When you're trying to cope with MS at the same time, it can be a scary experience, rife with uncertainty. Knowing there are people around you who can help you cope, answer your questions, and be there when you need them can be life-changing. With the right support, and the understanding of others, people with MS can live independent lives and take advantage of the same opportunities as everyone else.

We bring the MS community together like no other organisation, through our local networks, events, online forums and social media. We'll continue to make sure people with MS can connect with each other, and with us, to help them navigate the bad times, as well as enjoy the good.

Our five year objectives

- We will review our work across the UK, ensuring that it enables all people affected by MS to connect – with each other and with us – in a way which suits their needs.
- We will increase awareness and understanding of MS amongst the general public, and those involved in supporting people affected by MS.
- We will seek to minimise the financial impact of MS on people's lives, through campaigning for a welfare system that is appropriate for people affected by MS, and considering our own role in providing support and advocacy.

Rachel, Jon and Sandra volunteer with their local MS Society branch, bringing the MS community together in Lambeth and Southwark. Together they provide the friendship and mutual support that helps people affected by MS live their lives to the full.





Supporting families and carers

The families and carers of people with MS will have access to the support they need.

Supporting families and carers

The impact of MS often reaches far beyond the person who has it. Many people with MS rely on family and friends for care and support, whether it's occasional help with the shopping or daily help to get dressed. Supporting someone with MS can, at times, be a demanding role, and it's imperative that families and carers get all the support they need to deal with the day-to-day uncertainty of living with MS.

We'll make sure that services recognise the impact MS can have on everyone whose lives are touched by it, and that support is available where and when it's needed.

Our five year objectives

- Family members, partners and friends who support someone with MS will understand the importance of recognising their formal role as a carer (where appropriate) in order to access relevant and timely support and information from statutory services and other providers.
- We will have developed partnerships that enable carers of people with MS to access relevant and specialist support, information, compassion and peer advice that will validate and underpin their caring role.
- Families and carers will be informed of their rights to a carers assessment and encouraged to seek this assessment of their own needs.
- We will have influenced health and social care professionals to provide quality services that lessen the impact on families and carers, recognising them as partners in care and involving them in decision making.

Ann was diagnosed with MS when her daughter Georgina was very young. They had access to brilliant support from professionals, family and friends, but they know not everyone is as fortunate.





Greater certainty about the future

People with MS will have
greater certainty about
how their condition
will progress



Greater certainty about the future

Imagine living with the uncertainty of MS – not knowing from one day to the next if you'll develop a new and unfamiliar symptom, such as losing your sight or being unable to move. If you knew what was going to happen, you might be able to plan and prepare, but MS doesn't warn you in advance.

Life with MS can be scary and unpredictable, but research into what causes the build-up of disability could help bring much greater certainty for people with MS. We'll invest more in research to help give people the increased certainty that could make all the difference.

Our five year objective

- We will have improved our understanding of the progression of MS, including the factors that are associated with a more or less rapid disease course.

Danielle works for the MS Society, ensuring that our local volunteers have the information and resources they need. She's been living with MS since 2001, and hopes for greater certainty about how her condition will progress, so that she can make important decisions about her future.





Making it happen

Our people

Our people – our staff and our volunteers – are our greatest assets. We'll empower them to achieve our goals by making sure they've got the resources and skills they need, and can clearly see the difference their work makes. We want to make volunteering for us the best experience money can't buy, so we'll improve how we support all our volunteers to get the most out of their role.

Our effectiveness

We'll make the best use of technology to enable our staff and volunteers to share information and ideas, and bring the MS community together online. We'll ensure that our systems and processes allow us to work in the most effective and efficient way possible.

Our profile

We've built up a strong community over the years which brings thousands of volunteers and people affected by MS together locally, online and through our forums and social media. Our campaigns community is a strong voice in UK and national politics, helping us achieve some key wins. However to make our vision a reality, we need to build a movement for change, and mobilise the whole MS community to help us achieve our goals.

Our income

Our strategy is ambitious and aspirational, and requires us to increase our investment significantly if we are to achieve our goals. One way we will do this is through a major appeal raising funds for MS research. To achieve our goals, we'll mobilise more people and donors to give and fundraise in different ways, each of which is appropriate to them.

We need you!

We can't achieve our goals on our own – we need you to join us. Together, we can beat MS.

Donate

Your donation will make a huge difference to the lives of people affected by MS by helping to fund vital research and support services like our MS helpline.

You can set up a monthly direct debit, make a single donation or find out about giving through your salary.

 **0800 100 133**

 **supporterservices@mssociety.org.uk**

Send a cheque made payable to the **MS Society**, to 372 Edgware Road, London, NW2 6ND. Please include a note with your name and contact details.

Fundraise

There are lots of fun ways you can raise money for our life-changing work. From baking cakes to giving up chocolate or running a marathon, we'll be with you every step of the way.

 **fundraising@mssociety.org.uk**



Leave a gift in your will

Forward thinking today could help beat MS tomorrow. Many supporters generously leave us gifts in their wills, enabling us to fund research that could bring us closer to a cure.

 **legacies@mssociety.org.uk**

Become a member

Join the MS Society as a member and add your voice to 35,000 others.

 **membership@mssociety.org.uk**


Partner with us

Corporate partnerships make a crucial contribution to our work while offering fantastic benefits for your organisation. We'll work with you to create a partnership that is innovative and unique, and inspires all your employees to join the fight against MS.

 **mscorporate@mssociety.org.uk**

Volunteer

Become an MS Society volunteer and join an amazing team of people using their skills and interests to make a difference to the lives of people affected by MS.

 **volunteering@mssociety.org.uk**

Work for us

Our staff are key to our success. Without their commitment, dedication and skill, we simply wouldn't be able to deliver on our ambitious plans. In return, we offer a vibrant, progressive environment where you can make a difference you'll be proud of.

 **jobs@mssociety.org.uk**

Get involved


For more information, visit www.mssociety.org.uk/get-involved or call us on **020 8438 0700**



Multiple Sclerosis Society


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