

#### **About MS**

More than 11,000 of us in Scotland have MS. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way. We're driving research into more – and better – treatments for everyone. Together, we are strong enough to stop MS.

### Introduction

More than 11,000 people in Scotland have multiple sclerosis, making it more common than most other countries in the world. 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.

The Scotland Strategy sets out how we will work to enable everyone with MS to have the best life possible, supporting good health and wellbeing at the different stages of a person's journey with MS. We will develop communities and networks to build resilience. And support, to help them respond to the fluctuating and progressive nature of MS.

This strategy is a new direction and plan for Scotland. We want to mobilise the MS community to collectively stop MS, while strengthening our position as a UK wide organisation which understands what it is like for people with MS living in Scotland.

The Scotland Strategy focuses on the aims and objectives for Scotland over the three years from 2018 to the end of 2020. We will make sure this strategy and accompanying operational plans align with the new MS Society Corporate Strategy from 2019 onwards. The outcomes and impact of this strategy seek to ensure that every individual in Scotland with MS has the best quality of life possible.

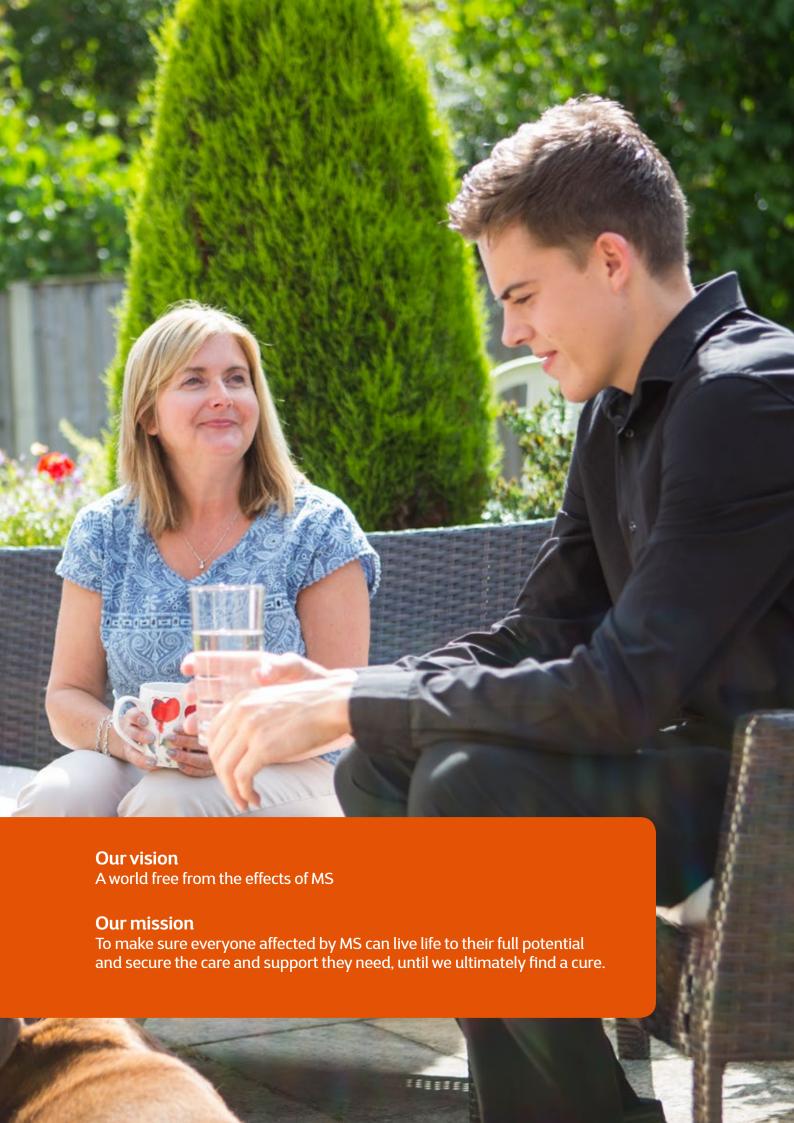
This strategy is our commitment to the MS community in Scotland. Together we can Stop MS, please help make our vision a reality.



Mary Douglas
Chair Scotland Council



Morna Simpkins
Scotland Director



# What we'll achieve through the Scotland strategy

Throughout the UK we share a common mission, vision and set of values. Our Strategy "Together to Beat MS" (2015 – 2019) sets out an ambitious UK wide direction for how we will improve outcomes for people affected by MS, underpinned by seven goals which are based on what people with MS told us is important to them.

Our Scotland strategy outlines distinctive objectives to ensure we realise the opportunities brought about by the operating environment and the increased policy divergence between Scotland and the rest of the UK.

Over the next three years the MS Society in Scotland will transform the way we offer support to people with MS in Scotland to make sure they have the best quality of life and improved health and care outcomes during the key moments in their journey from diagnosis. We will do this by developing new products, services and support which will aim to build resilience, skills, knowledge and confidence.

### Our approach

Several common themes and values run throughout our work to support people living with MS. These themes and values guide what we do, how we work, and the decisions we make:

- We work alongside people affected by MS - People affected by MS are, and will continue to be, at the heart of our decisions and our work
- We work with other organisations

   We know we can't achieve
   everything by ourselves. Working alongside others will be crucial to achieve our goals.
- We focus on areas where we can have the greatest impact -Our resources are finite. We must ensure we use our resources in the best and most effective way, which means prioritising what we do.
- We understand what we want to achieve - Being clear about what we want to achieve, and the progress we're making, is fundamental to our success

- We reach out to everyone affected by MS - We exist to support everyone affected by MS. We actively work to reach and engage with all individuals and communities affected by MS. from all walks of life.
- We tailor our approach We work internationally, across the UK, regionally and locally to beat MS, always adapting our approach to the context and working towards shared goals

### **Our values**

**Bold -** We are brave and innovative. We're not afraid to take risks and speak out, even when it is not easy. We are pioneering and dynamic in our approach to achieving our goals. We will campaign and push boundaries, and will not give up until we have beaten MS.

**Expert -** People with MS are experts in their own condition. We bring together their own experience and knowledge, along with that of staff, volunteers and professionals, and the best available evidence, to improve the lives of people affected by MS.

Ambitious - We do not accept the status quo. We set high standards and work hard to reach them, driving real change. We push the boundaries and are positive about beating MS.

**Together -** We achieve success by working with the whole MS community. We are collaborative and inclusive in our approach to succeed in delivering our goals. Everything we do shows we support and care about each other.

### Our goals

To make our vision a reality, we're working to achieve seven goals, ordered according to the priorities of people living with MS. Our goals form the heart of our strategy from 2015 to 2019. More than 3,000 people with MS helped set them, they are embedded in our work and resonate with people affected by MS, supporters, volunteers and staff.

# WE WILL – Our commitment to the MS community in Scotland

By implementing the Scotland Strategy:

- We will use robust evidence to achieve transformational social change by telling a compelling story about the reality of living with MS in Scotland
- We will make sure people with MS can access the right treatment options at the right time regardless of where they live in Scotland.
- We will understand and challenge prescribing barriers for people accessing DMTs. People with MS will feel supported and informed to be equal partners in treatment decisions.
- We will be a sector leader in ground breaking MS research in Scotland.
   We will raise the profile of research to increase fundraising to Stop MS.
- We will influence the government, health and care professionals and the public to ensure that legislation, policies, practices, service provision and attitudes change especially in relation to health and care, treatments and financial security.
- We will work to ensure that people with MS are not negatively impacted financially because of living with MS.
- We will work to make sure people with MS have access to high quality, trusted information and support throughout their MS journey by being the go to organisation in Scotland. We will make sure people with MS can have good, positive and open conversations about

- MS and feel empowered and informed to talk about living with MS.
- We will build on existing and initiate new services which are designed in partnership with the MS Community to build resilience, confidence and support behaviour change. From support through our helpline, practical tools, personalised emotional support and self-management to new services for people newly diagnosed and facilitating peer support.
- We will build a strong community of people with and affected by MS who support each other, share experiences, maintain and develop their social networks and work together to Stop MS.
- We will continue to highlight the needs of carers, work in partnership to promote Carers week, highlight changes to Carers Allowance and support carers through the existing national and local services, e.g. grants programme, helpline, signposting to local groups and information resources.
- We will harness the power of digital to improve lives of people affected by MS and reach more people to offer the information and support they need to feel connected and informed.
- We will grow our income and maximise the skills, talents and assets of our staff, volunteers and people with MS because together we can Stop MS.



### **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.

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.

- We will improve access to DMTs from 57% (2016) to 70% by 2020.
- We will test new ways of tackling prescribing barriers across the whole of Scotland, through information provision, behaviour change and service development, tackling the unwarranted variation that exists.
- We will continue to campaign to make sure all treatments and therapies specifically licensed for MS are routinely available on the NHS.
- We will support the submission of new MS medicines to Scottish Medicines Consortium via patient submissions.

- We will enable and support Scottish researchers to communicate their research to people affected by MS across Scotland in an accurate and accessible manner through our media channels, group events and research talks.
- We will promote our reputation as a leading research funder across Scotland through our media channels and fundraising communications and groups.





### **Goal 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.

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.

- We will make sure the new social security system in Scotland understands and responds to people with MS through introduction of lifetime awards for those with progressive MS and assessment criteria that are realistic and not burdensome.
- We will remain a key playerincluding through our leadership role in the Neurological Alliance of Scotland - in influencing the Scottish Government's programme of work, including the National Action Plan for Neurological Conditions and National Clinical Standards for Neurology.
- We will continue to support the Cross Party Group on MS to achieve increased understanding and awareness of MS within the Scottish Parliament, cementing our reputation as thought leaders within Scotland.

- We will make sure the needs of people with MS are heard and met, championing personcentered care and "no decision about me without me".
- We will have piloted, through restricted funding, new services for people affected by MS.
- We will further develop our impactful Living Well with MS self-management programme to provide individuals with the skills and confidence to manage their MS, including a digital offer.
- We will continue to develop our MS Active Together Programme to encourage more people with MS to engage in physical activity.
- We will support the growth and reach of our MS Helpline in Scotland.



### **Goal 3: Preventing MS**

Progress in research means that fewer people will develop 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.

- We will promote the research we fund across Scotland through our media channels, fundraising communications, research talks and events.
- We will develop public and political understanding of our work to fund research.



### **Goal 4: Quality Information**

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

Quality information underpins all our work. It's important as an end in itself, but also as a means to make informed choices and decisions about treatment, care and support, from medicines to benefits. Information can empower people living with MS to self-manage their condition, become active partners in their care, and increase their participation and independence. The way people choose to access information is changing, with online and mobile access becoming the first choice for many. There are big opportunities for innovation, but along with this comes a responsibility to ensure the digital revolution doesn't leave anyone with MS behind.

- We will make sure our national information services can respond to the needs of people affected by MS in Scotland by developing high quality Scottish specific information resources that meet their needs.
- We will understand the changing landscape of devolution and the impact that has on our communities information needs.
- We will increase the knowledge and awareness of our research programme and build the knowledge and skills of people with MS through our annual Living with MS events.





### Goal 5: A strong community, independent lives

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

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.

- We will support our local networks to grow and modernise their local service provision including new and innovative work to meet the needs of people affected by MS by providing support to utilise digital processes, increasing the number and reach of services, social groups and one off activities.
- We will support our groups to grow their income.
- We will increase the reach of the Grants Programme in Scotland.
- We will increase our engagement of with our campaigns community, creating interesting and relevant content.

- We will build on our First Person Voice programme, putting the voices of people living MS at the centre of our campaigns, media work and communications.
- We will continue to use social media platforms to give a loud voice to the MS community and increase the reach of our campaigns. We will engage in new technologies and understand how they can help us reach and involve the MS community.
- We will build our #MSSuperstars fundraising community, encourage and facilitate peer support as well as focus on encouraging supporters to become repeat fundraisers.



### Goal 6: Supporting families and carers

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

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.

- We will continue to support carers through existing national and local services, e.g. grants programme, MS Helpline, signposting to local groups and information resources.
- We will work in partnership to promote Carers Week to highlight the needs and issues affecting carers in Scotland.
- We will communicate the changes to Carer's Allowance in Scotland, encouraging people supporting someone with MS to claim the benefits they are entitled to.





### Goal 7: Greater certainty about the future

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

Imagine living with the uncertainty of MS – not knowing from one day to the next if you'll develop a new and unfamiliar symptom, like 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 three year objectives:

 We will promote our work as a leading funder of MS Research across Scotland through all channels. By 2020 we will be recognized as a research funder in the Charity Parliament Monitor Survey.

## Making it happen to achieve our objectives!

- We will build upon our credibility and reputation and will invest our time and resources wisely, demonstrating the impact of our work to our key stakeholders including staff, people affected by MS, donors, supporters and the public.
- We will deliver a successful launch of the Stop MS public appeal in Scotland with support from volunteers, media, corporates and supporters.
- We will evaluate and continuously improve our partnership working and identify opportunities of expanding existing fundraising relationships.
- We will create more volunteering opportunities and work to make sure our volunteers feel more engaged.
- We will ensure that our Scotland Council members are recognised as our strong ambassadors and that they represent the diversity of the MS community in Scotland.

- We will ensure the voices and views of people affected by MS are listened to and contribute to the development and delivery of high quality and relevant services which address the needs of people living with MS.
- We will make sure we use digital approaches effectively to maximise our ability to collaborate, extend reach, communicate and continuously learn
- We will increase involvement and empowerment of people affected by MS in all areas of our work.
- We will continue to work and extend involvement with other third sector partners such as SCVO, Institute of Fundraising, Health and Social Care Alliance and Neurological Alliance of Scotland and identify new ways to collaborate.
- We will ensure Legal and Regulatory compliance across all areas of work, including GDPR.
- We will work as one team, collaborating and supporting each other to Stop MS.

We need you!

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

### **Donate**

Your donation will make a huge difference to the lives of people living with MS by helping 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 MS Society to MS Society, Ratho Park, 88 Glasgow Road, Ratho Station, Newbridge, EH28 8PP

### **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.

msfundraising@mssociety.org.uk

### Leave a gift in your will

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

legacies@mssociety.org.uk

### Become a member

Be part of a national society to stop MS, 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.

msfundraising@mssociety.org.uk

Volunteer, including our Engagement Involvement and Empowerment programme

Volunteer with us and join an amazing team of people using their skills and interests to make a difference to the lives of people living with MS.

volunteering@mssociety.org.uk



### We're the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS. Together, we are strong enough to stop MS.

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### ► Let's stop MS together

#### Multiple Sclerosis Society.

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