MS-UK Strategy
2024 - 2026

MS-UK
Supporting your MS journey

Our vision - our hope for the future

A world where people affected by multiple sclerosis live healthier and happier lives.

Our mission - the difference we want to make

To improve understanding of multiple sclerosis and provide support where it is needed most.

Our values

Our values were created five years ago in close conversation with people affected by MS, our staff, and trustee board. We reviewed these in 2023 as part of our strategic planning and agreed that each is firmly rooted in the charity and continues to drive all that we do across the charity.

Community-led
The voices of people affected by multiple sclerosis inform all our work

Independent
We do not accept funding from sources that may or can be perceived to jeopardise our ability to act in the best interests of people affected by MS

Professional
We are knowledgeable and provide high-quality services

Unbiased
We will always be balanced in the information we share

Non-judgemental
We respect an individual's right to make choices for themselves

Supportive
We treat everyone fairly, with respect, care and compassion

After thorough research and discussion with our community and at board meetings, it was agreed that we will continue not to accept funding from pharmaceutical organisations to assure all in our community that we will always put their best interests first.

Our purpose

MS-UK was founded by John and Jean Simkins in 1993, both having survived previous partners who lived with multiple sclerosis (MS). Not content with simply waiting for a cure to be found, they set up our charity to support people to live well with the condition. Since then, we have been providing the MS community with the information and support they need to live happier and healthier lives, to make a difference today and every day, for as long as we are needed.

MS is a neurological condition affecting the central nervous system creating a wide range of symptoms which vary greatly from person to person. These can include visual disturbances, fatigue, pain and mobility problems to name a few. There are around 130,000 people living with MS in the UK. Much of the MS population do not have access to suitable treatments or care, therefore they must learn to manage their condition and its mental health impacts themselves.

We work with the MS community, supporting them to make the right choices for themselves about how to manage the impact of their MS and live a life as close as possible to how they wish.

I am so impressed by the way MS-UK has grown from those early days. Today it is bursting with new ideas and developments and a friendly, positive approach'
– John Simpkins, founder of MS-UK

Recent years have thrown many additional challenges in to the mix, above and beyond those traditionally associated with maintaining a small charity. The pandemic and cost of living crisis have provided some turbulent times for the charity. We are pleased to have weathered these storms and have emerged in a position where we have held on to our focus of listening to the MS community, yet transformed into a charity, that having embraced what digital technology has to offer, is now able to support many more hundreds of people than ever before.

We know that offering support online is vital for people with MS, as not only does it mean we can reach people across the UK, but we can also help those that are less able or unable to travel to in person support whether due to transport or their symptoms.

We've also heard that people want to be able to make a donation towards the cost of our activities and in the last year have built this function within our website, whilst also maintaining access for those not in a position to make a donation.

We are committed to ensuring we do not leave anyone unsupported and will ensure there are non-digital channels for accessing our information and support.

Our services support people like Lisa, this is her story...

'I have relapsing remitting MS. I have so many symptoms. I get a lot of pain, and I trip and fall quite often. At times my head is full of mush. I am not able to multitask – I forget the simplest instructions and find I have to continually talk myself through everything.

'I was given the news that I had MS over the phone, when human care and contact was perhaps at its lowest due to the pandemic.

'I felt helpless, despondent, and teary. I was alone and alienated.

'After a couple of months, the local MS nurse gave me information about MS-UK, and then the game changed.

'Now, suddenly, I was able to meet up with others out there who were experiencing similar things to me, both physically and mentally. I found large spaces of love and gratitude within this new community.

'It sounds strange, but I cannot express how liberating this was. The fear of what might happen, the grim fight of acceptance within, the feeling of vulnerability and sometimes the utter darkness were pins blown apart by the ball of MS-UK.

'I attended my first Peer Pod to meet others, and in the space of a year,

I have attended all the online courses and information sessions I've been able to.

'Two of my favourites have been a poetry course with Georgi Gill, and an introduction to Tai Chi. I've also been on some awesome introduction to meditation courses – I love them!

'I truly believe that there is a gift in everything. Sometimes it's blooming hard to find it, or to figure out what on earth is going down. MS-UK has helped me connect with others, stay positive and find the space inside that is peaceful. Now, there's a gift.'

Our focus for the next three years

Holistic self-support activities

Our conversations with people affected by MS have enabled us to identify a wide range of activities we will provide to support people's health and wellbeing. This includes our regular classes such as exercise and yoga for all abilities, and many new lifestyle and leisure activities. We will deliver these ourselves, and partner with experts in other fields to ensure the highest standard of quality.

We will also be exploring how we can provide more mental health support online, in addition to our regular mindfulness and meditation courses.

As well as offering these activities live, we will look to provide as much as possible as 'catch up' or 'on demand', so people can take part at a time that best suits them. Wherever we can, we will also incorporate these activities into our information resources and New Pathways magazine.

Unrivalled MS information

We have always been at the forefront of ensuring our information enables people to make choices for themselves. We will never shy away from a subject and do not judge people for their choices, including how to live with MS, whether that includes drug treatments, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will continue to share our expertise and that of the MS community themselves, through our helpline, website, choices booklets and New Pathways magazine. We will also provide many more online information sessions on subjects such as symptom management, welfare benefits and lifestyle.

Working with the MS community we have identified new areas of information that we will incorporate into our work over the next three years.

Compassionate emotional support

Central to the work of our helpline team, is providing emotional support. Life with MS can be emotionally challenging at any stage of the condition and any time in life. Our helpline team are trained in how to provide professional emotional support and this will remain a key focus for the charity.

Relatively new to us is the creation of our Peer Support Service. We now have 14 groups of people that meet online to support one another and become a group of friends who just get it. Though it is incredibly difficult for many to take that first step and reach out, our aim in the coming years is to encourage more people to join our groups, make connections and feel less alone.

Lived experience-led education and awareness-raising

Sharing people's experiences is vital to ensuring that our educational and awareness-raising activities make a meaningful impact. Each year we will create a wide range of campaigns to raise awareness of MS aimed at the MS community and the general public.

We will continue to provide our two eLearning courses, MS Awareness and Counselling People with MS, which powerfully combine our expertise in MS with real people's stories.

We will also be expanding the number of training webinars we provide to professionals working in health and social care and related fields, so they can better tailor their work to people living with MS.

> **Truly makes me feel like this charity is listening and cares about directly helping us**

Achieving success

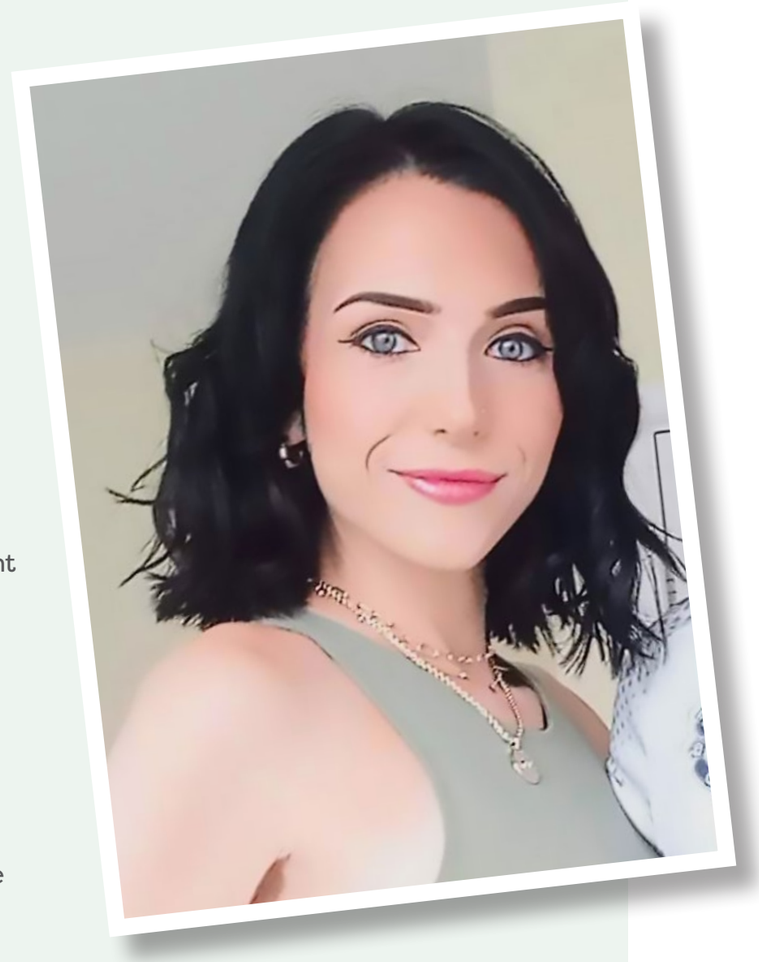
To fulfil our ambitious plans, we will need to invest in our infrastructure so we can streamline our systems, automate our processes, and ultimately, better communicate with our community and supporters.

Central to our success is recruiting and retaining the right people to deliver our work and support the charity. We will treat our staff and volunteers as well as we treat our beneficiaries, including looking after their health and wellbeing and personal development.

We will continue our investment in marketing so that we can ensure our services and fundraising opportunities are well taken up or attended.

We will look to widen and deepen our relationships with current and new supporters and increase the range of ways in which people can support the charity both financially and in kind. We must raise more funds if we are to support more people.

When Kayleigh was newly diagnosed she called our helpline...



'I first discovered MS-UK via social media. I was looking for some support and information as I was going through acceptance around my illness.

'I've used MS-UK's Helpline on a number of occasions when I have needed emotional support or practical advice. It has been brilliant for me. The staff at the other end of the phone are informative and very friendly.

'I felt like I was talking to a supportive friend when I rang the helpline. I always feel better after speaking to someone who understands. I've recommended the helpline to friends with multiple sclerosis (MS) who need support or information. The MS-UK team are amazingly supportive – my partner has also benefitted from calling.

'It has helped me get a better understanding of treatments, make sense of my symptoms, find support and connect with others with MS in the UK. It has improved my mood a great deal when I've called the helpline and I've felt supported.

'To anyone reading this, I'd say – don't hesitate to pick up the phone or go online and reach out for support, you'll feel so glad you did.'

> **I felt like I was talking to a supportive friend when I rang the helpline**

Could you support our work?

Volunteer

There are lots of volunteering opportunities at MS-UK from supporting a fundraising event to becoming a peer pod volunteer or even writing for our magazine, blog and socials.

Work together

Whether you work at an organisation that could provide expertise or in-kind support in your field, or could work with us to benefit the MS community in another way.

Fundraise

Take part in one of our fundraising events, create your own activity or get your workplace involved – we have lots of fun ways to support the charity and make a difference for people with MS.

Donate

You can make a single or regular donation online or over the phone anytime and know that every penny we raise will go toward supporting the MS community.

To find out more visit our website, give us a call, or drop us an email. Details are on the back page. Thank you.

Stay in touch

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